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ABSTRACT

The Medicaid program and its impact on the long-term care of developmentally disabled individuals were the subject of this hearing, held in September 1986. The hearing examined the current funding provided through Medicaid, the range of services delivered, and the most appropriate setting for long-term care of the developmentally disabled (institutional care or community care). A 57-page report prepared by the Congressional Research Service of the Library of Congress summarized the issues concerning Medicaid and other Federal services for persons with mental retardation and developmental disabilities. Representatives from the Health Care Financing Administration and the Office of Human Developmental Services presented U.S. government positions. Public witnesses represented university programs, state agencies, and national associations. Additional prepared statements, letters, and supplemental materials represented state developmental disabilities and advocacy agencies; local, state, and national voluntary organizations; and concerned parents. (JDD)

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MEDICAID FINANCING OF SERVICES FOR DEVELOPMENTALLY DISABLED PERSONS

HEARING

BEFORE THE

SUBCOMMITTEE ON HEALTH

OF THE

COMMITTEE ON FINANCE
UNITED STATES SENATE

NINETY-NINTH CONGRESS

SECOND SESSION

SEPTEMBER 19, 1986

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MEDICAID FINANCING OF SERVICES FOR DEVELOPMENTALLY DISABLED PERSONS

FRIDAY, SEPTEMBER 19, 1986

U.S. SENATE,
COMMITTEE ON FINANCE,
SUBCOMMITTEE ON HEALTH,
Washington, DC.

The hearing was convened, pursuant to notice, at 9:35 a.m. in room SD-215, Dirksen Senate Office Building, Hon. David Durenberger (chairman) presiding.

Present: Senators Durenberger, Chafee, Heinz, and Mitchell.

Also present: Senator James J. Exon.

[The press release announcing the hearing, and the prepared written statements of Senators Dole, Durenberger, Chafee, and Mitchell and a background paper prepared for the committee follows:]

[Press Release No. 86-070; August 7, 1986]

FINANCE SUBCOMMITTEE TO EXAMINE MEDICAID FINANCING OF SERVICES FOR DEVELOPMENTALLY DISABLED PERSONS

The Medicaid program and its impact on the long-term care of developmentally disabled individuals will be the subject of a hearing before the Subcommittee on Health, Bob Packwood (R-Oregon), Chairman of the Committee on Finance, accounced today.

Senator Packwood called for a hearing in order to examine carefully the current funding provided through the Medicaid program, the range of services delivered and the type of setting most appropriate for the long-term care of developmentally disabled persons.

The hearing has been scheduled for Friday, September 19, 1986, at 9:30 a.m. in Room SD-215 of the Dirksen Senate Office Building in Washington.

Senator Packwood noted that in 1985, $4.7 billion in Federal and State Medicaid funds had been spent providing care and services to 146,000 developmentally disabled people living in intermediate care facilities for the mentally retarded (ICF/MR) while in 1976, expenditures totalled $635 million, and served 89,000 persons. In addition, non-institutionalized developmentally disabled people receive a variety of services in the community.

Senator Packwood stated that given the size of the ICF/MR program and its rapid growth over the last ten years it is time to evaluate where and how the funds are being spent and whether services are being provided in the setting most appropriate to meet the needs of the individuals receiving services.

The Chairman indicated that Senator Dave Durenberger (R-Minn.) will chair the Subcommittee hearing. It is expected that the Department of Health and Human Services, and other Federal agencies providing services to developmentally disabled persons will present testimony. State organizations and national groups with a variety of viewpoints will be expected to testify.

REMARKS OF SENATOR DAVE DURENBERGER
SUBCOMMITTEE ON HEALTH
MEDICAID AND THE DEVELOPMENTALLY DISABLED
SEPTEMBER 19, 1986

Today's hearing will take a close look at the Medicaid program and the needs of developmentally disabled individuals. This is a very complicated and emotionally charged issue to deal with. The needs of developmentally disabled individuals call forth our most important responsibility as public policymakers -- how we respond to those needs is a test of our society's character and moral fiber.

In order to properly address the needs of these individuals, we have to "begin at the beginning" and ask a number of very basic questions -- How many developmentally disabled individuals are there? What services are available to them through federal and state programs? What services do they need, and in what setting?

This last question takes us to what quickly becomes the heart of any discussion of Medicaid and the developmentally disabled -- and that is the issue of institutional care versus community-based services.

I feel strongly that today's hearing should not be reduced to an "either/or" situation, that we should not consider ourselves here to declare a preference for either institutions or community services. That kind of dichotomy or polarization obscures the real issue.

What is that issue? Simply this -- developmentally disabled individuals have different needs which require different services in different settings. I believe the real challenge we face as policymakers is not to establish a preference for one setting over another, but to adopt a policy which allocates federal resources appropriately along the continuum of services that the developmentally disabled need.

Does the Medicaid program have a bias toward institutional care that is out of line with the needs of the clients? Does that bias limit the expansion or availability of community services that might be more desirable and effective for some developmentally disabled individuals? What can be done to remove any existing bias, and to instead promote the availability of community services - without restricting the availability of institutional care for those who really need it? These are the kinds of questions I think we have to ask.

I have a statement here from the Minnesota Coalition of Parents and Friends for Community Residential Services, prepared by Galen Pate, the courageous father of a young woman with multiple disabilities. I would like to share a part of Galen's statement with you, because I believe it represents the view and experience of a lot of concerned parents and family members.

-more-

Galen's daughter Elizabeth has been diagnosed as having cerebral palsy, profound mental retardation, and a seizure disorder. Because of the level of care that his daughter requires, Galen was not able to care for her in his home. Because he wanted to be closely involved in his daughter's development, Galen began working with other families in his community to develop a group home.

His original desire was to set up a small home for about six people, but in the early stages of planning, it became evident that the cost for meeting the needs of a profoundly handicapped person would require a home designed on a larger scale, with a higher staffing ratio, and more costly physical plant requirements. While he is still as involved as ever in Betsy's life, his experience has tempered his earlier feelings about what type of setting would provide Betsy with the best care.

Galen and other members of the Minnesota Coalition of Parents and Friends for Community Residential Services have worked hard to develop community residential facilities. But their experience has shown that other kinds of facilities are also needed - particularly for those individuals who are severely and profoundly mentally retarded, medically fragile, or in need of significant behavior management.

I think Galen's group speaks for many of us when it says: "The system needs to be expanded in a planned and thoughtful manner so that the quality of care currently available to our children is not compromised through a rush to reduce the size of the facility or the size of the federal Medicaid budget. The range of service options needs to be expanded, not limited, so that our children and all other children who will likely follow them continue to have an effective array of choices available."

I wanted to share this statement with you because I know that this is an emotionally charged issue and that many people here today have loved ones whose very lives are on the line when we talk about changes in federal programs. To you, let me say that I have heard and understood your concerns as devoted parents and supportive family members. I am not approaching today's hearing with any preconceptions as to the outcome it should produce.

I simply believe that it is time to ask a very basic question -- how can federal programs best ensure that the developmentally disabled receive high quality services in a way which maximizes their freedom, their safety, and their individual potential to learn and grow?

We have a long list of witnesses today - we've tried to accommodate as many different areas of expertise as possible. In order to hear from everyone and to have time for questions, we will have to adhere strictly to the five minute rule - so I will have to ask all our witnesses to be brief. Your full written statements will be made a part of the record. Let's proceed to our first panel.

19th

(1:30)

STATEMENT OF SENATOR DOLE

MR. CHAIRMAN, I THANK MY COLLEAGUE, THE SENATOR FROM MINNESOTA FOR HOLDING THIS HEARING ON SERVICES FOR DEVELOPMENTALLY DISABLED PERSONS AND THE MEDICAID PROGRAM. I AM CONFIDENT THAT THE DISTINGUISHED AND CAPABLE ASSEMBLY OF WITNESSES WE WILL HEAR TODAY WILL BE OF GREAT ASSISTANCE TO US AS WE EXPLORE THE MANY ISSUES AND MANY PERSPECTIVES THAT COME TO BEAR ON THIS IMPORTANT SUBJECT.

AS MANY WHO ARE TESTIFYING HERE TODAY KNOW, MY INVOLVEMENT WITH AND SUPPORT OF THE DEVELOPMENTALLY DISABLED POPULATION IN MY OWN STATE OF KANSAS AND

THROUGHOUT THESE UNITED STATES GOES BACK A LONG WAY. TODAY WE ARE GOING TO LOOK BACK OVER THOSE FIFTEEN YEARS OF SUCCESS AND ACHIEVEMENT IN FEDERAL SUPPORT PROGRAMS FOR PERSONS WITH MENTAL RETARDATION AND DEVELOPMENTAL DISABILITY. NO ONE CAN CHALLENGE THE FACT THAT WE HAVE COME A LONG WAY NOR CAN THEY DENY THERE IS MUCH FOR ALL OF US TO LEARN. THAT'S WHY WE ARE HERE. WE MUST DRAW ON OUR EXPERIENCE AND CAPTURE THE PROGRESS BEING MADE ON MANY FRONTS, FROM TECHNOLOGICAL ADVANCES TO MORE COST EFFECTIVE DELIVERY MODES, TO MORE HUMANE SERVICES.

I KNOW FULL WELL SOME OF THE DIFFICULT ISSUES WE ARE FACING IN MY OWN STATE. RECENTLY, THERE WAS A REVIEW AND SUBSEQUENT SHIFT IN THE ELIGIBILITY OF CERTAIN INDIVIDUALS AT ONE INTERMEDIATE CARE FACILITY. SOME INSTITUTIONALIZED RESIDENTS WERE REQUIRED TO MOVE TO COMMUNITY-BASED CARE. THE MOVE

BROUGHT WITH IT NEW AND GREATER OPPORTUNITIES ALONG WITH SHORTER COMMUTES FOR SOME FAMILIES AND LOVED ONES OF THE FORMER RESIDENT. HOWEVER, FOR SOME, THE SCENARIO WAS LESS THAN ROSEY. COMMUNITY BASED CARE IS NOT EASILY ACCESSIBLE. IN THIS CASE THE CHANGE CAN BE A WRENCHING ONE. WHILE I AM CONFIDENT THE PEOPLE WHO HAVE WORKED ON THIS PROBLEM IN KANSAS HAVE BEEN AS SUPPORTIVE AND HELPFUL AS POSSIBLE, WE WERE NOT ABLE TO ESCAPE THE ANGUISH, CONFUSION, ALARM AND ANXIETY THAT RESULTS WHEN DISRUPTIONS OCCUR.

ABOVE ALL WE MUST REMEMBER THAT WE HAVE A GREAT OPPORTUNITY TO MAXIMIZE THE QUALITY OF LIFE FOR THOSE ENTRUSTED TO OUR CARE.

STATEMENT BY
SENATOR JOHN H. CHAFEE
ON
S.2209: THE DISABLED PERSONS ACT

Dole – [illegible]

Mr. Chairman, I am a co-sponsor of S. 2209, The Disabled Persons Act which we are considering today. I commend my colleague from Kansas for his introduction of this proposal. This legislation is of great importance to disabled Americans who want to participate in many facets of life, including the opportunity to be productive members of the work community. When it is passed, disabled individuals will have something to cheer about - Congress will finally acknowledge that individuals with disabilities should be supported and assisted in their efforts to join the workforce rather than discouraged because they cannot afford the high cost of their disability-related health care needs without some help from federal programs.

Because it is such an important issue, I also addressed this problem in my legislation, S. 873, The Community and Family Living Amendments of 1985. Unfortunately, that bill does not seem to have as good a chance for final passage this year as S.2209, so I am pleased we are addressing this issue today.

Prior to 1980, disabled individuals ran the risk of jeopardizing their supplemental security income (SSI) eligibility, which which determines an individual's eligibility for Medicaid, if they were engaged in any substantial gainful activity -- an income producing job. If an individual who had a severe handicap successfully performed any income producing activity, the was viewed as a demonstration that he or she no longer lacked the capacity for work. Before January 1, 1981 gross earnings above $300 were a basis for denial of SSI benefits.

In 1980 as part of the Social Security Act Amendments, Congress authorized a three year demonstration project providing special cash benefits and continued Medicaid eligibility to encourage disabled SSI recipients to attempt to return to work. In 1984 these provisions, known as Section 619, were extended through June 30, 1987. We are here today to discuss the permanent authorization of SSI and Medicaid benefits under Section 1619.

I fully support efforts to encourage disabled individuals who wish to join the work force to have the chance to do so. But we must be certain that barriers that discourage their participation, such as the possible loss of SSI or Medicaid benefits, are eliminated. Access to the work community is critical in order to assist disabled persons to pursue full and active lives.

We are in an era of changing technology and experience. Our understanding of the capabilities of those with disabilities is changing quickly. We have made tremendous strides in our ability to help those with disabilities to learn and to participate in many different facets of life. These individuals represent a highly

MOTIVATED, DEPENDABLE WORK FORCE. THIS LEGISLATION WILL GIVE THEM THE OPPORTUNITY TO FULFILL THEIR POTENTIAL.

George Mitchell

Statement of Senator George J. Mitchell
Health Subcommittee Hearing on
Medicaid Financing of Services for
Developmentally Disabled Persons
September 19, 1986

Mr. Chairman, I want to thank you for scheduling this hearing today to examine Medicaid financing of services for developmentally disabled persons in our society.

In recent years we have witnessed a significant change in the treatment of the developmentally disabled in our communities. Thousands of persons who had been in large public institutions have now been placed in community-based settings. This movement towards community-based treatment facilities has been a very positive experience for many of our citizens, but with this movement away from large institutions has come new challenges.

Individuals placed in community-based settings may be in greater need of new skills including socialization, self-help and other adaptive skills necessary to reside successfully in home and community-based facilities.

It is important that this Committee has as accurate a view as possible of the current situation with regard to the financing of services for the developmentally disabled. We must look at the type of facilities available, and make sure that our current funding structure best meets the needs of this population.

I am pleased that so many witnesses are with us today, persons and organizations that represent a variety of perspectives on how best to provide services for the developmentally disabled. I would especially like to welcome Bonnie-Jean Brooks, the Executive Director of Opportunity Housing in Bangor, Maine, who is representing the National Association of Private Residential Facilities for the Mentally Retarded.

I look forward to the testimony to be presented by our witnesses and anticipate working with the Committee to continue to improve the important programs and services for the developmentally disabled.

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SERVICES FOR PERSONS WITH MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES: BACKGROUND INFORMATION AND DISCUSSION OF ISSUES

Prepared for the use of the
Senate Committee on Finance

Mary F. Smith
Specialist in Social Legislation
and
Richard Price
Specialist in Social Legislation
Education and Public Welfare Division
September 16, 1986

ABSTRACT

The major source of Federal support for persons with mental retardation and developmental disabilities is the Medicaid program, title XIX of the Social Security Act. This paper describes Medicaid services and other Federal programs serving this population and discusses issues in the delivery of services to these persons.

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SERVICES FOR PERSONS WITH MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES: BACKGROUND INFORMATION AND DISCUSSION OF ISSUES

INTRODUCTION

Services for persons with mental retardation and related conditions are funded through a variety of Federal programs. The Medicaid program, title XIX of the Social Security Act, provides the major share of Federal resources for these persons. This paper describes the population of persons with mental retardation and related conditions, identifies the major sources of program support, and presents the amount expended. The development of services to this population is presented beginning with the movement of some persons out of large isolated custodial facilities into more socially integrated, community-based settings. Although there is steady movement to increase community services, there has also been a need expressed to maintain some level of comprehensive care in larger facilities for some of these disabled persons. Issues regarding services to this disabled population are discussed and relevant legislation is summarized.

I. HISTORY

Over the past 100 years many large institutions were built to provide care for mentally retarded persons. These institutions, which frequently served many hundreds of residents, provided 24-hour maintenance and, in some facilities, therapeutic care. The institutions generally were built in rural areas not adjacent to towns or cities, and for this reason, normal community involvement of the institutionalized residents was not generally possible. Prior to the 1950s, such institutional services were virtually the only available source of services for persons with mental retardation, and many families were encouraged by their physicians to institutionalize severely handicapped newborns at birth. A General Accounting Office (GAO) report characterized institutional care as follows:

> Until the 1960s, mentally disabled persons who could not afford private care had to rely primarily on public institutions for their care. Conditions in these institutions generally were harsh. Treatment programs were limited; living quarters were crowded; few recreational or social activities were available; and individual privacy was lacking. In general, the institutions served as custodial settings, often with unpleasant conditions, and many people remained institutionalized for years. 1/

1/ U.S. General Accounting Office. Summary of a Report. Returning the Mentally Disabled to the Community: Government Needs to do More; Report to the Congress by the Comptroller General of the United States. HRD-76-152A, Jan. 7, 1977. Washington, 1977. p. 1.

In the 1950s parents of retarded children began to organize and to encourage the development of community services so that their handicapped children could receive specialized developmental services while living at home. These parents also worked to bring about improvements in institutions. This parents' group is the Association for Retarded Citizens. The movement to improve community services and institutional conditions for mentally retarded persons was supported by President Kennedy who appointed a panel to study the issue and report to the President. The panel recommended that institutional care be restricted to those retarded persons whose specific needs can be met best by this type of service. The panel further recommended that local communities, in cooperation with Federal and State agencies, undertake the development of community services for retarded persons. Abuses and neglect of retarded institutionalized persons were reported in the press, and during the 1960s and the 1970s efforts were made nationwide to improve conditions in institutions, expand alternatives to institutionalization, and move residents from institutional to community settings. This became known as the deinstitutionalization movement.

Over the past 15 years there has been a steady decline in the number of mentally retarded persons served in public institutions. Services have been developed in the community to help provide care for persons coming out of institutions and to offer an alternative to persons who may otherwise have required institutionalization.

Several pieces of landmark legislation have been enacted by the Congress to provide services and protections for persons with mental retardation and related conditions. In 1971, Congress authorized Federal Medicaid funding for care provided in intermediate care facilities for the mentally retarded and persons with related conditions (ICFs/MR). ICFs/MR provide 24-hour care in a residential facility. The Medicaid program is a Federal-State matching program that provides medical assistance for low-income persons who are aged, blind, disabled, or members of families with dependent children. To receive funds, ICFs/MR must meet Federal certification standards established under the Medicaid program. Regulations published in 1974 (42 C.F.R. 442 subpart G) were intended to ensure a safe and therapeutic environment and include provisions for adequate staffing, health and safety requirements and minimum specifications for individual space and privacy. An updated regulation published March 4, 1986, is intended to increase the focus on active treatment of institutionalized persons and to improve the ability of State survey agencies to assess the quality of care. Today the Medicaid program is the largest source of Federal support for services provided to persons with mental retardation and related conditions.

In 1975, the Developmentally Disabled Assistance and Bill of Rights Act (P.L. 94-103), included provisions intended to improve services to mentally retarded and other disabled persons in institutions. This law required that States submit a plan to eliminate inappropriate placement in institutions and improve the quality of institutional care. State plans were also required to support the establishment of community programs as alternatives to institutionalization.

Also in 1975, the Education for All Handicapped Children Act (P.L. 94-142), required States to provide educational and supportive services in the least restrictive environment for all handicapped children ages 3 to 21.

In 1980, the Civil Rights of Institutionalized Persons Act P.L. 96-247, gave the U.S. Attorney General explicit authority to initiate and intervene in litigation involving the constitutional rights of institutionalized persons. The Attorney General is authorized to intervene if he believes that deprivation of rights is part of a pattern of denial, if the suit is of general public importance, and if it is believed that institutionalized persons are being subjected to "egregious or flagrant" conditions which deprive such persons of any rights, privileges or immunities under the Constitution or laws of the United States.

II. BACKGROUND INFORMATION

A. Definition of the Target Population

Medicaid law authorizes Federal support for certain institutional services for "the mentally retarded or persons with related conditions." Mental retardation is defined by the American Association of Mental Deficiency as significantly subaverage intellectual functioning existing with deficits in adaptive behavior and manifesting during the developmental period (during childhood or adolescence). The current Medicaid regulation defining "persons with related conditions" is based on the previous and current definitions of "developmental disability" as set forth in the Developmental Disabilities Act.

A 1974 Medicaid regulation issued to cover care in ICFs/MR defined "persons with related conditions" by referencing the definition of developmental disability as set forth in a 1970 statute. 2/ This definition was originally based on specific impairments including mental retardation, cerebral palsy, epilepsy, and related neurological conditions. The current definition of developmental disability enacted in 1978 is a functional definition that describes the adaptive capacity of eligible persons, but does not include specific impairments. A developmental disability is currently defined under

---

2/ Developmental Disabilities Services and Facilities Construction Act.

the Developmental Disabilities Act as a severe, chronic disability which begins by the time a person is a young adult and which substantially limits the person's ability to function independently. The statutory definition states: 3/

> The term "developmental disability" means a severe, chronic disability of a person which:
> (A) is attributable to a mental or physical impairment or combination of mental and physical impairments;
> (B) is manifested before the person attains age 22;
> (C) is likely to continue indefinitely;
> (D) results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency; and
> (E) reflects the persons' need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.

Because this definition does not include specific impairments, it can be interpreted to include mental illness, and mental illness is not covered under Medicaid's ICF/MR benefit. Medicaid provides funds for services to the mentally ill apart from the ICF/MR program. Therefore, the Health Care Financing Administration (HCFA) promulgated a new regulation to define "persons with related conditions." (51 Federal Register 19181, published May 28, 1986.) This definition includes components of the former and the current definitions of developmental disability and specifically excludes mental illness:

> "Persons with related conditions" means individuals who have a severe, chronic disability that meets all of the following conditions:
> (A) It is attributable to:
> cerebral palsy or epilepsy or any other condition, other than mental illness, found to be closely related to mental retardation because this condition results in impairment of general intellectual functioning or adaptive behavior similar to that of mentally retarded persons, and requires treatment or services similar to those required for these persons.

3/ Section 102(7) of the Developmental Disabilities Assistance and Bill of Rights Act.

(B) It is manifested before the person reaches age 22.
(C) It is likely to continue indefinitely.
(D) It results in substantial functional limitation in three or more of the following areas of major life activity: self-care, understanding and use of language, learning, mobility, self-direction, capacity for independent living.

In summary, it might be said that the Medicaid program's support for persons with conditions related to mental retardation is intended for persons whose conditions cause severe intellectual or behavioral deficits requiring services similar to those required by mentally retarded persons.

This paper will use the term persons with mental retardation or developmental disabilities (MR/DD) to mean persons who are eligible for a variety of Federal programs; the term includes those mentally retarded and persons with other related conditions that are eligible for Medicaid services as described above.

III. MEDICAID SERVICES FOR MR/DD PERSONS

The major source of Federal support for care for MR/DD persons is the Medicaid program, authorized under title XIX of the Social Security Act. The Medicaid program is a Federal-State matching program which provides medical assistance for low-income persons who are aged, blind, disabled, or members of families with dependent children. Eligibility for Medicaid is generally linked to actual or potential receipt of cash assistance under the Federal Supplemental Security Income (SSI) program for the aged, blind, and disabled or the federally assisted Aid to Families with Dependent Children (AFDC) program. Most MR/DD persons who become eligible for Medicaid do so on the basis of their disabled status under SSI. It should be noted that under SSI disability rules, an individual is not considered to be disabled if he or she is able to engage in "substantial gainful activity" (SGA), which the Secretary of Health and Human Services (HHS) has defined as average counted earnings of $300 or more per month. For children under 18, disability must be of comparable severity.

All States cover the "categorically needy" under their Medicaid programs. In general, these are persons receiving cash assistance under SSI or AFDC. States have the option of limiting Medicaid coverage of SSI recipients by requiring them to meet any more restrictive eligibility standard that was in effect on January 1, 1972 (before implementation of SSI). These States are commonly referred to as "209(b) States" in reference to the statutory provision which gives them the option to use their 1972 eligibility standards instead of SSI's. States choosing the more restrictive criteria must allow applicants to deduct medical expenses from income in determining eligibility. States may also cover certain additional persons as categorically needy who do not actually receive cash assistance. These might include persons who would be eligible for cash assistance, except that they are residents in medical institutions (such as skilled nursing facilities or intermediate care facilities). Many MR/DD persons who become eligible for medical assistance under Medicaid are considered categorically needy recipients. 4/ It should be noted that under SSI (and therefore Medicaid) eligibility rules, an institutionalized individual is no longer considered to be living in the same household as his/her parents or spouse after the first full month of institutionalization, and income of the parents or spouse is not considered as available, unless actually contributed, for the care of the institutionalized person.

States are required to offer the following services to categorically needy recipients under their Medicaid programs: inpatient and outpatient hospital services; physician services; laboratory and x-ray services; skilled nursing facility (SNF) services for individuals over 21; home health services for those entitled to SNF care; early and periodic screening, diagnosis, and treatment (EPSDT) for individuals under age 21; and family planning services and supplies. States may also provide coverage for a broad range of optional

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4/ Generally MR/DD persons who are categorically needy recipients are permanently and totally disabled individuals eligible to receive SSI assistance. In addition, MR/DD persons may become eligible for Medicaid assistance if they are "medically needy." The medically needy are aged, blind, disabled, or members of families with dependent children (1) whose income and/or resources are slightly in excess of standards for SSI or AFDC cash assistance, and (2) who incur medical expenses which reduces their income to the State's medically needy income eligibility level.

services, including drugs, intermediate care facility (ICF) services, and eyeglasses. States are permitted to establish limitations on the amount of care provided under a service category (such as limiting the number of days of covered hospital care or the number of physician services). Because States have flexibility in defining the services that will be covered under their Medicaid plans, the actual services that an MR/DD Medicaid recipient receives will therefore vary from State to State.

In general, HCFA, which, together with the States, administers the Medicaid program, does not collect data on the utilization by MR/DD eligible recipients of most categories of services covered by the States in their Medicaid programs. However, HCFA does report data on certain institutional services frequently used by this population. In addition, data from a special study on services used by the MR/DD population are discussed later in this paper.

A. Institutional Services Covered under Medicaid for MR/DD Individuals

Under Medicaid, States provide institutional services to MR/DD persons primarily through facilities known as intermediate care facilities for the mentally retarded (ICFs/MR). Medicaid law defines in section 1905(c) of the Social Security Act an ICF as an institution which: (1) is licensed under State law to provide, on a regular basis, health-related care and services to individuals who do not require the degree of care and treatment which a hospital or skilled nursing facility is designed to provide, but who, because of their mental or physical condition require care and services (above the level of room and board) which can be made available to them only through institutional facilities; (2) meets standards prescribed by the Secretary as he finds appropriate for the proper provision of this care; (3) meets standards of safety and sanitation which are established by the Secretary in regulation in addition to those applicable to nursing homes under State law; and (4) meets requirements for protection of patients' funds.

Medicaid statute also specifies in section 1905(d) that intermediate care facility services may include services in a public institution (or distinct part thereof) for the mentally retarded or persons with related conditions if, among other things: (1) the primary purpose of the institution (or distinct part thereof) is to provide health or rehabilitative services for mentally retarded individuals and the institution meets such standards as may be prescribed by the Secretary; and (2) the mentally retarded individual is receiving active treatment. These facilities are known as ICFs/MR.

In FY 1985, only one State, Wyoming (in addition to Arizona which is operating an alternative demonstration program), did not cover ICF/MR services under its Medicaid program. According to HCFA approximately 150,000 persons were served in ICFs/MR in FY 1985. Federal and State expenditures for ICF/MR care totaled $4.7 billion in FY 1985.

Some MR/DD persons are also served under Medicaid in ICFs and SNFs, that are not ICFs/MR. According to HCFA, ICFs and SNFs are generally not considered to be appropriate settings for care for MR/DD individuals. However, if an MR/DD individual has reached the capacity of his intellectual and social development or requires primarily skilled medical care, then an ICF or SNF may be an appropriate setting for his care. HCFA estimates that up to 10 percent of residents of ICFs and SNFs are mentally retarded persons. (In FY 1985, there were 826,966 recipients of ICF care and 547,051 recipients of SNF care. According to the HCFA estimate, about 140,000 of these persons were mentally retarded.

B. Home and Community-Based Services for the MR/DD Individuals

Section 1915(c) of Medicaid law authorizes the Secretary of HHS to waive certain Medicaid requirements to allow States to provide a broad range of home and community-based services to individuals who would otherwise require, and have paid for by Medicaid, the level of care provided in a SNF or ICF. Home and community-based services waivers are frequently referred to as 2176 waivers after the section in the Omnibus Budget Reconciliation Act of 1981, P.L. 97-35, which authorized them. Although certain home and community-based services could be covered by the States under their Medicaid plans prior to the amendment, the 1981 legislation provides States with increased flexibility to offer an expanded range of such services, to determine individuals to be covered, and to define the geographic areas to be served.

Under the this waiver authority, HCFA is allowed to waive two specific Medicaid requirements: (1) a requirement that Medicaid services be available throughout a State, and (2) a requirement that covered services be equal in amount, duration, and scope for certain Medicaid recipients. By allowing the Secretary to waive these requirements, States are given flexibility to offer selected 2176 home and community-based services in only a portion of the State, rather than in all geographic jurisdictions as would be required absent the waiver, and to offer selected services to certain State-defined individuals eligible for Medicaid assistance, rather than offering such services to all eligible individuals.

In order to receive approval for a waiver, States must provide a number of assurances to the Secretary, including one requiring that the estimated average per capita expenditure for medical assistance under the waiver for those receiving wavered services in any fiscal year not exceed 100 percent of the average per capita expenditure that the State reasonably estimates would have been incurred in that year for that population if the waiver had not been granted. In addition, States must assure that necessary safeguards (including adequate standards for provider participation) have been taken to protect the health and welfare of individuals provided services under the waiver and to assure financial accountability for funds expended for these services.

States may cover the following services under 2176 waivers: case management, homemaker/home health aide services, personal care, adult day health, habilitation services, respite care, 5/ and such other services requested by the State and approved by the Secretary. These other services have included home modifications, non-medical transportation, nutritional counseling, and congregate and home-delivered meals.

The client groups most frequently served by States under the waiver have been the aged/disabled and MR/DD. Since the inception of the program, HCFA has approved 144 waivers in 47 States. As of August 25, 1986, 104 approved waivers are active in 44 States. Of the total active waivers, 46 are currently serving MR/DD persons in 35 States. A HCFA survey of active waivers as of September 30, 1985, showed that 21,109 MR/DD persons were being served at that time. The most frequently offered services to MR/DD individuals under the waiver program have been case management, habilitation, and respite care. A provision in the Consolidated Omnibus Budget Reconciliation Act of 1986, P.L. 99-272, defined habilitation services, for purposes of 2176 waivers, as services designed to assist individuals in acquiring, retaining, and improving the self-help, socialization, and adaptive skills necessary to reside successfully in home and community-based settings, including prevocational, educational, and supported

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5/ See Glossary at Appendix A for definitions of these terms.

employment services. 6/ Habilitation services provided under the waiver authority cannot include special education and related services as defined in the Education of the Handicapped Act which otherwise are available through a local educational agency, or vocational rehabilitation services 7/ which otherwise are available through a program funded under the Rehabilitation Act of 1973, as amended.

C. Standards for Assuring Quality Care for MR/DD Medicaid Recipients

As noted above, the Medicaid statute requires that services provided to MR/DD recipients, whether in the community or an institution, meet certain standards designed to protect the health and safety of the recipients of services.

1. Home and Community-Based Waiver Services

For home and community-based services provided under 2176 waivers, final regulations issued by HCFA March 13, 1985, require States to provide assurances that necessary safeguards have been taken to protect the health and welfare of the recipients of these services. The regulations specify that safeguards include adequate standards for all types of providers that furnish services under the waiver as well as standards for board and care homes where a significant number of SSI recipients are residing or likely to reside and where home and community-based services may be provided. If the State has licensure or certification requirements for any services or for individuals who furnish

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6/ Ibid.

7/ Ibid.

these services under the waiver, it must assure HCFA that the standards in the licensure or certification requirements will be met. The preamble to interim regulations on the waiver program pointed out that the regulations do not attempt to define these safeguards or to prescribe how they are to be developed. Rather they leave to the State the responsibility for determining what the necessary safeguards are, to define them or specify how they will be developed and implemented, and to explain how they satisfy the statute.

2. ICF/MR Services Under Medicaid

Medicaid statute requires ICFs/MR to meet certain definitional requirements as well as standards prescribed by the Secretary for safety and sanitation and for the proper provision of care. These standards were originally published by the Secretary in regulations in 1974 and have not been significantly revised since then. HCFA has proposed a general revision of these standards in a rule published March 4, 1986. According to HCFA, this revision is intended to increase the focus on the provision of active treatment services to clients, clarify Federal requirements, maintain essential client protections, and provide State survey agencies with a more accurate mechanism for assessing quality of care.

Current standards prescribe requirements for staffing, resident living areas, residents' rights, medical, nursing, and dental services, food and nutrition services, among others, which an ICF/MR must meet in order to participate in Medicaid.

Regulations also define in greater detail certain other requirements contained in Medicaid law for ICFs/MR. For example, regulations require that active treatment provided by ICFs/MR include: (1) regular participation by the recipient in professionally developed and supervised activities, experiences, or therapies; (2) an individual written plan of care that sets forth measurable goals or objectives for desirable behavior and a program for reaching them; (3) an interdisciplinary professional evaluation; (4) reevaluation at least annually by the staff involved in carrying out the resident's individual plan of care to review progress made toward meeting the plan's objectives, the appropriateness of the plan, continuing need for institutional care, and consideration of alternative methods of care; and (5) an individual postinstitutional plan of care that is developed before discharge and that specifies appropriate services, protective supervision, and other follow-up services needed in the resident's new environment.

States must certify that ICFs/MR meet these various requirements and standards before Federal payments may be made for care provided to eligible recipients in these institutions. Medicaid law requires the State Medicaid agency to contract with a State survey agency to determine, through inspection, whether facilities meet the requirements for participation in the Medicaid program. The survey agency may certify a facility that fully meets requirements and standards for up to 12 months. Survey agencies may also certify a facility for participation if it is found to be deficient in one or more standards if the deficiencies, individually or in combination, do not jeopardize the health and safety of patients and if the facility submits an acceptable plan of correction for achieving compliance within a reasonable period of time. A facility with deficiencies that do not jeopardize the patient's health and safety may continue to be certified under Medicaid for a period of up to 12 months while it corrects the deficiencies.

In the Omnibus Reconciliation Act of 1980, P.L. 96-499, Congress authorized the Secretary of HHS to "look behind" a State's survey of nursing homes and make an independent and binding determination regarding a facility's compliance with program requirements and standards. If the Secretary finds that a facility fails to meet program requirements and standards, he is authorized to terminate the facility's participation until the reason for the termination has been removed and there is reasonable assurance that it will not recur. In FY 1985, HCFA completed 464 look-behind surveys of ICFs/MR. In that year, 72 facilities, or 15 percent of the total number inspected by HCFA, were notified of some form of possible adverse action by HCFA. Eight facilities were actually terminated or voluntarily withdrew their participation following HCFA inspections. In FY 1986, HCFA has completed 514 look-behind inspections as of August 1, 1986, and 80 facilities, or 12 percent of the total inspected, have been notified of the possibility of some kind of termination proceedings.

In addition, before the enactment of P.L. 96-499, if a State survey agency made a determination that a facility could not comply with requirements and standards for care, the only available sanction was to terminate the facility's provider agreement. P.L. 99-499 provided HCFA and State Medicaid agencies with an alternative intermediate sanction for deficient ICFs and SNFs. When a finding is made that a facility no longer substantially meets the law's requirements and standards of care, and deficiencies do not immediately jeopardize the health and safety of the facility's patients, the Secretary and/or State may, instead of terminating the facility's participation in the program, refuse to make payments on behalf of eligible individuals later admitted to the facility. However, if it is determined that the deficiencies do immediately jeopardize the health and safety of the facility's patients, the Secretary or State must terminate the facility's participation in the program. If the decision is made to deny program payment instead of terminating a facility's participation, the facility must achieve substantial compliance with program requirements or be found to have made a good faith effort to correct its deficiencies by the end of the 11th month following the month when a decision is made to deny payment. Final regulations implementing these provision were published July 3, 1986, and became effective August 4, 1986.

The Consolidated Budget Reconciliation Act of 1985 (COBRA), P.L. 99-272, enacted April 7, 1986, provided States additional options under which ICFs/MR that are found by the Secretary to have substantial deficiencies that do not pose an immediate threat to recipients' health and safety may remedy those deficiencies. These provisions in COBRA allow the State Medicaid agency to submit written plans to the Secretary either to make all necessary corrections in such facilities, including staff and physical plan corrections, within 6 months of the approval date of the plan, or to reduce permanently the number of beds in certified units within 36 months of the approval date of the plan. These options apply only to correction and reduction plans approved by the Secretary within 3 years after the effective date of final regulations. Proposed regulations for these COBRA provisions were published by HCFA July 25, 1986.

IV. FEDERAL EXPENDITURES FOR PROGRAMS SERVING THE MR/DD POPULATION

It is estimated that in FY 1985, $4.7 billion in Federal funds was used to support various services for the MR/DD population. 8/ Of this Federal total, $2.7 billion or 57 percent, was used for room and board, health, and rehabilitative services delivered in ICFs/MR. The next largest Federal estimate was $930 million for Medicaid services delivered to MR/DD persons who were not in ICFs/MR.

The following services may be delivered in or out of institutions, but are primarily community-based services. Human development services accounted for $347 million and included grants to States for developmental disabilities programs and social services. State developmental disabilities services are focused primarily on community living services, employment-related activities, child development services, and case management services. State grants for

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8/ Data in this paragraph are from: Braddock, David, Ph.D. Federal Spending for Mental Retardation and Developmental Disabilities. Public Policy Monograph Series no. 7. University of Illinois at Chicago. July, 1985. p. 31 and 71. This research was partially supported by the National Institute of Handicapped Research, U.S. Department of Education and by the Administration on Developmental Disabilities, U.S. Department of Health and Human Services. The data for this report were obtained directly from the States and, to a lesser extent, from HCFA. This research provides the most comprehensive analysis of expenditure data for MR/DD persons by source of support.

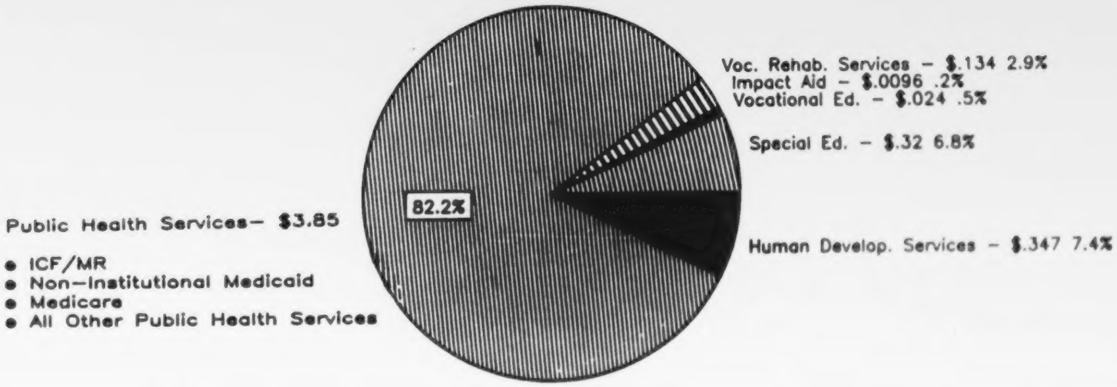
In addition to the Federal funds discussed here, States provide funding for services for the MR/DD population that is in excess of the Federal amount. The voluntary sector also provides funds for MR/DD services.

social services, authorized under title XX of the Social Security Act, may be used to assist the MR/DD population in areas such as protective services, day care services for adults, training, and employment services. For special education services to MR/DD children, $320 million in Federal dollars was expended. Vocational rehabilitation services used to train and place MR/DD adults into employment accounted for $134 million. Chart 1 shows the total Federal support for MR/DD services in FY 1985, 82.2 percent of which is used for public health services. Chart 2 shows Federal spending for public health services for MR/DD persons in FY 1985. Table 1 summarizes individual eligibility and services covered under the major Federal programs serving the MR/DD population.

In addition to Federal funds, States provide funding for services to MR/DD persons. A recent study estimates that in FY 1984, State funds accounted for 54 percent of the cost of institutional services and 70 percent of the cost of community services. 9/

9/ Braddock, David, et al. Public Expenditures for Mental Retardation and Developmental Disabilities in the United States. State Profiles, Public Policy Monograph Series no. 5. University of Illinois at Chicago. Dec. 1984. p. 19.

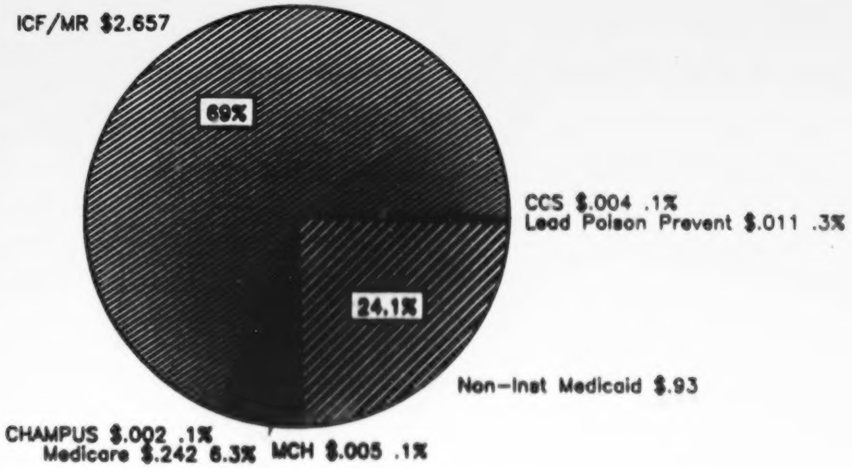
CHART 1. FEDERAL SUPPORT FOR MR/DD SERVICES: FY 1985
(Dollars in Billions)



Total Services Funding: $4.685 Billion

Source: Reproduced from Braddock, David, Ph.D. Federal Spending for Mental Retardation and Developmental Disabilities. Public Policy Monograph Series no. 7. The University of Illinois at Chicago. July 1985. p. 31.

CHART 2. ESTIMATED FEDERAL SPENDING FOR MR/DD PUBLIC HEALTH SERVICES: FY 1985, BY PROGRAM
(Dollars in Billions)



Total Expenditures: $3.85 Billion

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Source: Reproduced from Braddock, David, Ph.D. Federal Spending for Mental Retardation and Developmental Disabilities. Public Policy Monograph Series no. 7. The University of Illinois at Chicago. July 1985. p. 71.

TABLE 1. Major Federal Support for MR/DD Services: Services Covered and Eligibility

Program	Services covered	Eligibility
Medicaid ICF/MR	Health and rehabilitative services, including active treatment in an institution certified as meeting various requirements and standards.	Generally, disabled persons receiving cash assistance, or if in an institution, eligible to receive cash assistance under SSI, or the medically needy who incur medical expenses which reduce their income to the State's eligibility level.
Medicaid Not ICF/MR	Services which States are required to offer to certain recipients, including inpatient hospital services, physicians services, laboratory and x-ray services, and other optional services which States may cover such as prescription drugs, eyeglasses.	Generally disabled persons receiving cash assistance under SSI, or the medically needy.
Human development services (delivered in or out of institutions)	Developmental disabilities services including child development, employment-related services, alternative community living arrangement services, and case management services. Also included are developmental disabilities interdisciplinary training and protection and advocacy grants.	Persons meeting the definition of developmental disability.
	This category also includes a wide range of social services under the Social Services Block Grant, as well as Child Welfare Services, Headstart, and the Foster Grandparent Program.	These programs are generally available to MR/DD and other persons.

TABLE 1. Major Federal Support for MR/DD Services: Services Covered and Eligibility--continued

Program	Services covered	Eligibility
Special education (delivered in or out of institutions)	Includes funds for special education and related services for handicapped children in State-operated or State-supported schools; funds for State grants to provide special education services to all handicapped children; and funds for preschool incentive grants. Special education includes classroom instruction, instruction in physical education, home instruction, and instruction in hospitals and institutions. Related services include transportation and such developmental, corrective, and other supportive services as may be required, as well as early identification and assessment of handicapping conditions in children.	Handicapped children means children with the following disabilities who require special education and related services: mental retardation, hearing impairments, speech or language impairments, visual impairments, serious emotional disturbance, orthopedic impairments, specific learning disabilities, other health impairments.
Vocational rehabilitation (delivered in or out of institutions)	Includes Federal allotments to State vocational rehabilitation agencies to provide comprehensive services to handicapped individuals including evaluation, physical and mental restoration, vocational training, special devices required for employment, job placement, followup services, and any other services necessary to make the handicapped person employable.	Handicapped individual means a person with a physical or mental disability which results in a substantial handicap to employment; the individual must be expected to benefit in terms of employability from the services provided.

V. COSTS AND NUMBER OF PERSONS SERVED IN RESIDENTIAL FACILITIES

A. Overview

There is no precise figure available of the number of MR/DD persons in the U.S. or of the number of mentally retarded or persons with related conditions eligible for Medicaid. The numbers presented below are based on persons served in different types of facilities, but do not include persons living with their families, many of whom would request services if there were additional community-based residential services available. There is lack of uniformity in the numbers presented below because data are from different agencies and represent different years. The numbers also overlap. The type of facilities that may care for MR/DD persons may be licensed by the State to provide some level of care and services. Among licensed facilities, some may be certified by Medicaid as ICFs/MR. Licensed facilities, including ICFs/MR, may be public or private. Unlicensed facilities would necessarily be private.

In FY 1982, 243,669 persons were served in licensed care facilities. This number includes public and private facilities, but does not include MR/DD persons in unlicensed facilities. In FY 1984, 109,827 persons were served in public institutions, most of which are ICF/MR certified. This number does not include persons served in private facilities. The number served in ICFs/MR, 158,616 in FY 1984, includes public and private ICFs/MR, but does not include those in facilities not certified to receive ICFs/MR funding. It is estimated that the number of persons potentially eligible for ICF/MR services is at least double the number currently receiving such services. Annual costs of ICF/MR services are presented and per diem ICF/MR costs are compared with costs in facilities not certified as ICFs/MR.

B. Estimate of Total Number of MR/DD Persons

A recently-published study of the total number of persons who could be eligible for ICF/MR services indicates that about 377,000, or slightly more than double the present number of persons, are potentially eligible. 10/ This number is based on an estimate of the number of severely and profoundly retarded persons in the U.S., on the assumption that ICF/MR services are most appropriate for this population. If mildly and moderately retarded persons are also target populations of Medicaid-funded community-based services, the potential eligible population could approximate 2 million, according to the author of the article cited above.

C. Number and Characteristics of MR/DD Persons in Licensed Care Facilities

A 1982 survey indicated that in that year there were 243,669 MR/DD persons served in some type of facility specifically licensed for the care of mentally retarded people: public or private institutions, nursing homes, supervised

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10/ Lakin, Charles and Bradley Hill. Target Population, from An Analysis of Medicaid's Intermediate Care Facility for the Mentally Retarded (ICF/MR) Program, Center for Residential and Community Services, University of Minnesota, Sept. 1985, p. 2-37.

group or individual living arrangement, foster care, and boarding homes. Table 2 shows the number of persons served by size of facility and the number of facilities in each size category.

TABLE 2. Number of Persons with Mental Retardation or Related Conditions Served in State Licensed Residential Facilities as of June 30, 1982

Number of beds in facility	Number and (percent) of persons served	Number of facilities
1-6 a/	33,188 (14)	10,469
7-15	30,515 (12)	3,393
16-63	25,691 (10)	1,098
64-299	45,709 (19)	495
300+	108,566 (45)	178
Total	243,669 (100)	15,633

a/ Facilities of six beds or fewer are mostly foster care arrangements.

Source: Lakin, Charles, Ph.D. Center for Residential and Community Services, University of Minnesota. From 1982 National Survev of Residential Facilities for Mentally Retarded People. (Survey supported by a grant from the Health Care Financing Administration (HCFA).)

D. Public Institutions

Large institutions originally built to provide 24-hour care to mentally retarded persons became, in many places, the only available residential facility for persons with severe cerebral palsy, uncontrolled epilepsy, autism and certain other severe, chronic or multiply handicapping conditions. Facilities providing institutional care for these MR/DD persons range in size from 16 to 2,000 beds, although about one half of all institutionalized MR/DD persons are in State-operated facilities of 300 beds or over.

Over the past decade, there has been a nationwide effort to move less severely disabled persons out of large public institutions and into small community-based facilities. As a result, the population of public institutions decreased 42 percent between 1970 and 1984, from 189,546 to 109,827. 11/

As disabled persons were transferred from institutions to community settings over the past decade, those remaining in public institutions tended to be the most severely handicapped persons. In 1982, 57.2 percent of the residents of public institutions were profoundly retarded, 23.8 percent were severely retarded, 12.3 percent were moderately retarded and 6.1 percent were mildly retarded. 12/ Those remaining in institutions were also more likely to have multiple handicaps. Of the institutionalized retarded persons: 12 percent were also blind; 6 percent were deaf; 41 percent had epilepsy; 21 percent had cerebral palsy; and 36 percent had an emotional handicap. In 1976, 34.4 percent of the residents of public residential facilities were multiply handicapped; this number had increased to 43.1 percent by 1982. The percentage of those with an emotional handicap nearly tripled during that period from 13.3 to 36.0 percent. In summary, of those residents remaining in public institutions, 81 percent are severely or profoundly retarded, 43 percent are multiply handicapped, and 36 percent have an emotional handicap.

The functional level of these institutionalized residents is characterized as follows:

- o 29 percent could not walk without assistance;
- o 61 percent could not dress without assistance;
- o 40 percent could not eat without assistance;
- o 28 percent could not understand the spoken word;

11/ See appendix B for the average daily population of persons in public residential facilities from 1970-1984.

12/ Data from Charles Lakin, Ph.D. University of Minnesota.

o 55 percent could not communicate verbally; and
o 40 percent were not toilet-trained.

E. Program Costs and Persons Served in ICFs/MR

In FY 1984, the most recent year for which such data are available, 158,616 MR/DD persons were served in the ICF/MR program at a cost of $2.6 billion in Federal expenditures. Table 3 indicates that ICF/MR expenditures, as a percentage of total Federal Medicaid expenditures, increased from 1 percent when the program began in FY 1972 to 13 percent in FY 1984. Although the ICF/MR program absorbed 13 percent of the Federal Medicaid dollars in FY 1984, its beneficiaries accounted for less than 1 percent of the persons served under the Medicaid program. The ICF/MR program grew rapidly in the first decade, and experienced an average annual rate of increase of over 18 percent between FY 1972 and FY 1981. This rate of growth has declined in more recent years, and averaged an annual 9 percent increase between FY 1981 and FY 1985. In FY 1985, there was only a 3 percent growth rate.

There is great variation in the extent to which States participate in the ICF/MR program. Of all beds licensed or operated by the States for care of the MR/DD population, the percentage of ICF/MR-certified beds ranged from a high of 98 percent in Minnesota to a low of 17 percent in West Virginia. Appendix C shows this percentage by State. It is estimated that in FY 1986, approximately 77 percent of the Federal ICF/MR funds are being used in public residential facilities and 23 percent are being used in private residential facilities. 13/

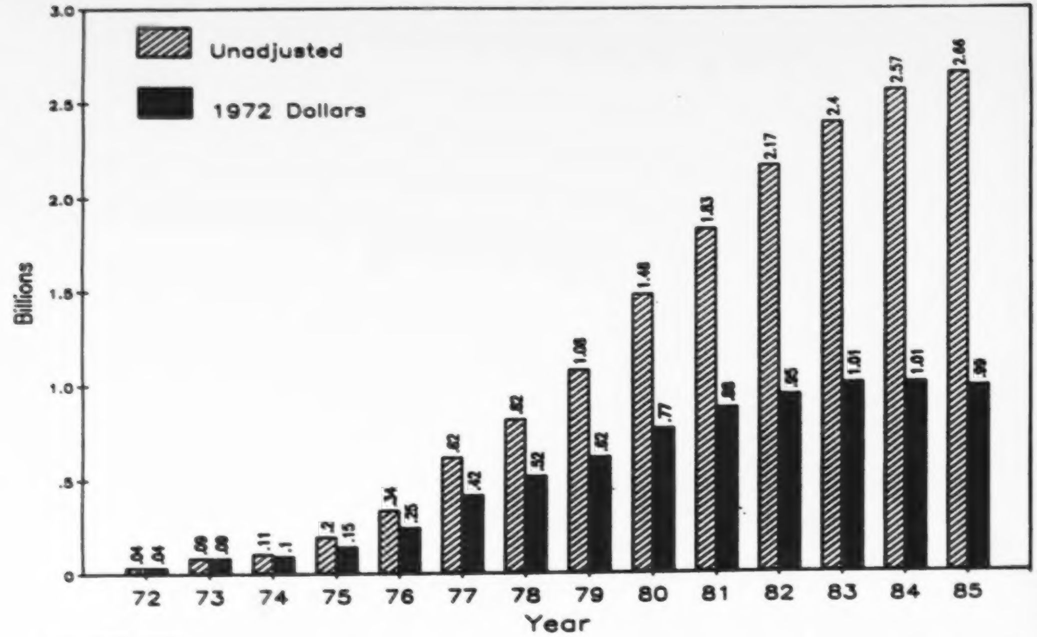
13/ Braddock, David, et al. Public Expenditures for Mental Retardation and Developmental Disabilities in the United States. State Profiles, Second Edition, FY 1977-FY 1986. Public Policy Monograph Series no. 29. University of Illinois at Chicago. Sept. 1986. p. 63.

TABLE 3. History of ICF/MR Reimbursements
($ in thousands)

Fiscal Year	Total Medicaid Federal Funding	ICF/MR Reimbursements Federal Share	ICF/MR as % of Total Federal Medicaid	ICF/MR Residents	Total Medicaid Recipients
1972 (est.)	$3,527,467	$36,872	1.05%	12,188	18,311,978
1973	4,838,260	92,181	1.91	30,472	19,998,566
1974	5,590,413	113,835	2.04	40,008	22,008,607
1975	6,873,890	195,174	2.84	55,033	22,413,309
1976	7,913,889	336,904	4.26	85,633	24,666,253
1977	9,114,477	615,337	6.75	100,823	22,929,873
1978	10,066,544	817,393	8.12	100,496	22,206,577
1979	11,458,642	1,080,462	9.43	115,168	21,536,715
1980	13,291,174	1,479,285	11.13	125,328	21,710,516
1981	15,739,472	1,833,670	11.65	173,764	21,979,638
1982	16,743,303	2,170,314	12.96	154,305	21,936,446
1983	17,751,945	2,395,178	13.49	155,194	21,493,000
1984	19,884,000	2,572,336	12.94	158,616	22,487,000
1985	22,116,000	2,657,000	12.01	--	23,114,000

Source: Braddock, David, Ph.D. Federal Spending for Mental Retardation and Developmental Disabilities. Public Policy Monograph Series no. 7, University of Illinois at Chicago, July 1985. p. 72.

CHART 3. FEDERAL ICF/MR REIMBURSEMENTS: FY 1972 - 1985



Source: Reproduced from Braddock, David, Ph.D. Federal Spending for Mental Retardation and Developmental Disabilities. Public Policy Monograph Series no. 7. The University of Illinois at Chicago. July 1985. p. 74.

F. Per Diem Costs by Type of Facility

Numerous studies have attempted to identify the per diem cost differential between institution and community-based residential programs for the MR/DD population. A recent assessment of 11 of these studies shows that while there were lower average per diem costs for community services, there was a wide and unexplained range of costs even in supposedly comparable settings with comparable clients. Higher than average costs were found for persons with severe and/or multiple disabilities and for school age disabled persons, regardless of service settings. As MR/DD persons moved from institution to community care settings, responsibility for funding of services shifted from Federal to State and local governments. Generally higher functioning levels were found among MR/DD clients served in the community, and there was an overall association between community programs and improved client outcomes. 14/

Facilities certified as ICFs/MR may maintain higher standards of care than non-certified facilities, and facilities of less than 16 beds tend to serve the less severely disabled persons. According to one major study (see Table 4), the most expensive facility was the State-operated ICF/MR with 16 or more beds. The ICF/MR-certified institutions of 16 or more beds provide services for persons who tend to be very severely impaired. The per patient per diem cost of a State-operated ICF/MR ranged from a high of $145 per day in the District of Columbia to a low of $40 per day in Kansas and Oklahoma. 15/ The cost of a

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14/ Kotler, Martin, et al. Synthesis of Cost Studies on the Long-Term Care of Health-Impaired Elderly and Other Disabled Persons: Executive Summary. Macro Systems, Inc., Silver Spring, Maryland, Sept. 16, 1985. See also footnote .

15/ See appendix D for ICF/MR per diem rates by State. The variation in per diem rate is based on differences in kinds and amounts of services provided and differences in salaries and other institutional expenses, according to a HCFA official.

privately operated non-certified residence of 15 beds or fewer was the least expensive option at $25 per day; this amount did not include the cost of community services received away from the residence.

TABLE 4. Per Diem Costs for Persons with Mental Retardation or Related Conditions Served in State Licensed Residential Facilities, FY82

Number of beds	Public facilities	Private facilities
16+ beds		
ICF/MR certified	$87	$51
Non-certified	73	39
1-15 beds		
ICF/MR certified	82	62
Non-certified	33	25

Source: Lakin, Charles, Ph.D. Center for Residential and Community Services, University of Minnesota. Telephone conversation with the author, June 21, 1985. Data from 1982 National Survey of Residential Facilities for Mentally Retarded People.

The differences in employee salaries and benefits account for some of the variation in per diem costs. Employees of State institutions tend to be unionized and to receive more employee benefits than do persons delivering care in community facilities, e.g., a 1982 cost study in Pennsylvania found that the average annual salary of an institution worker was $14,161 compared to $9,304 earned by community residential program workers. 16/ Institution fringe benefits amounted to 36.4 percent of base salaries whereas fringe benefits in community facilities were 21 percent of salaries. The specialization of labor

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16/ Longitudinal Study of the Court-Ordered Deinstitutionalization of Pennhurst Residents: Comparative Analysis of the Costs of Residential and Day Services within Institutional and Community Settings. Human Services Research Institute, Boston, Mass., Dec. 15, 1983. p. 57.

in institutions and the medical focus of institution staff are major factors contributing to increased staff costs in institutions.

Current and proposed ICF/MR regulations require a more intensive level of care and habilitation and training than is generally found in non-ICF/MR facilities. The level of care in ICFs/MR has been questioned by a study that found the level of care required in an ICF/MR to be more than was needed for certain institutionalized persons who could benefit from a more independent residential setting where less costly services would be more appropriate. 17/

17/ U.S. Department of Health and Human Services. Placement Care of the Mentally Retarded: A Service Delivery Assessment. National Report to the Secretary, Office of the Inspector General. Oct. 1981.

VI. SELECTED ISSUES REGARDING THE EXPANSION OF COMMUNITY-BASED SERVICES

A. Increased Demand for Community-Based Services for MR/DD Persons

Several factors contribute to the demand for increased community residential services and community-based daytime services: the movement of MR/DD persons out of institutions, the movement of young MR/DD adults out of special education classes, and the increased demand for community-based services by MR/DD persons who have been maintained at home and in non-medical board and care facilities.

Over the past 15 years, many MR/DD persons have been moved from care settings that fostered dependence and social segregation to settings that facilitate community integration and maximum independence. This philosophy is set forth in the Developmental Disabilities Act which is intended to promote independence, productivity, and integration into the community. The movement of MR/DD persons is facilitated by public and private efforts to develop group homes, daytime therapeutic programs, and employment opportunities. Daytime programs include day activity programs, in which productive work is not emphasized; sheltered employment, in which subminimum wages are paid in proportion to productivity; and supported employment, in which special supervision and assistance is provided to enable the disabled person to earn competitive wages. Experience has shown that many MR/DD persons who were previously institutionalized are capable of a degree of independent activity if the necessary training, supervision, and other assistance is provided. For example, many MR/DD persons who were previously determined to require institutional care are now living in small, supervised community-based residences, taking public transportation to sheltered or supported jobs, participating in community recreation activities, receiving social services where needed, and leading semi-independent lives. If a crisis should occur, the individual may require intensive attention or retraining, or may require temporary institutionalization. However, if the philosophy of the Developmental Disabilities Act is being implemented, the individual would be offered opportunities to re-enter a more independent living and working life style after the crisis was resolved.

The mandate that States provide special education to all handicapped children has generated rising expectation regarding the opportunities that will be available to these young people when they leave the school systems. Families accustomed to having educational and other support services available to their handicapped child see that with help, these persons are capable of some degree of independence and productivity. Therefore, as these young people leave school, their families are advocating for increased availability of group homes, supported employment, and the array of intervention services required to maintain the progress experienced during the developmental period. Because the major source of funds for adult MR/DD persons is the Medicaid program, advocates for MR/DD persons are looking increasingly to the Medicaid program to help support the array of services needed to sustain MR/DD persons in community-based settings. This raises a question about the appropriateness of the

Medicaid program as the funding source for certain of these community-based services, since Medicaid was originally intended to provide medical and medically-related services.

As discussed earlier, the number of MR/DD persons potentially eligible for ICF/MR services may be more than double the number currently receiving services. Persons being taken care by families or living in board and care facilities may not be getting the daytime habilitation services they need to progress into supported employment or other productive activity. If additional community-based services are made available, additional demand can be expected to arise on behalf of MR/DD persons.

The total number of MR/DD persons is affected by advances in medical care and life-saving devices, which may be having a dual effect on the incidence of MR/DD persons. (Data are not available to show the numerical effects of these influences.) For example, intensive care for premature infants allows some newborns to survive who would have died in the past. However, some of these infants are left with severe disabilities that require life-long care and treatment. On the other hand, amniocentesis allows parents to know the disability status of their unborn children, and this may reduce the incidence of certain kinds of disabling conditions, because of termination of pregnancy.

B. Appropriate Settings for Residential Services for MR/DD Persons

There is considerable disparity of opinion regarding the type of service setting considered most appropriate. Some professionals, parents of disabled persons and other interested and informed persons, feel that family-style or individualized living arrangements provide a superior residential and service setting for the needs of all MR/DD persons by providing personalized care in a more normal, community-based setting. According to this position, large facilities are dehumanizing and degrading and are often the locations of flagrant abuse and neglect. Because these institutions tend to be isolated from normal community interactions and normal role models, disabled persons can become less able to function in normal community settings after entering an institution, according to this argument. Some families of institutionalized persons would prefer to have their disabled family member in a more normal community setting near the rest of the family.

On the other hand, some professionals, parents of disabled persons, and other knowledgeable persons, have stated that not all MR/DD persons can be adequately trained and cared for in the community. According to this position, there should be available a continuum of care, ranging from small family-scale residences to high quality institutions, to meet the diverse needs of the severely disabled population. It is argued that the critical factors determining quality of care are quality of staff, staff-client ratios, active family involvement, and on-site health and therapeutic services, not the size or location of the residential facility. Some parents of institutionalized MR/DD persons feel that their family member is getting appropriate, effective care in an institution. These parents want the security that they feel they have in the institutional setting. Such parents want the assurance that their offspring will continue to receive care after the parents die. Some such parents fear that community services may become fragmented, may be discontinued, and may not provide the total care provided in one setting by an institution.

Litigation and legislation have focused public attention on abuses and deficiencies in institutions for MR/DD persons. There is general agreement that ICF/MR regulations have been instrumental in significantly improving conditions in institutions, and there are many institutions that provide appropriate services in safe, humane environments. However, testimony, presented at congressional hearings held in 1985, showed that abuse and neglect continue to be serious problems at some institutions for MR/DD persons. 18/ Witnesses told of physical and sexual abuse by other residents and staff, verbal abuse, self-destructive behavior of residents due to neglect, excessive use of medication, excessive solitary confinement, inappropriate use of mechanical restraint, untreated injuries, filthy and foul-smelling facilities, and inadequate reporting and correction of abuse by institution staff and administrators. Such abuse and deficiencies have convinced some persons that institutions are unsuitable settings for services for MR/DD persons. On the other hand, persons who favor the option of larger residential facilities advocate improvement in the quality of care delivered in institutions and the correction of deficiencies in these facilities. As discussed earlier, administrative actions have been taken to address these problems. Also, legislation has been introduced to help improve conditions in institutions. Congressional hearings have not been held on possible abuses in community-based facilities, and published, systematic studies are not available on this issue.

Although empirical research on institutional versus community care is not conclusive, most studies tend to support the contention that community-based services conducted in as normal a setting as possible are more effective than institutional services in promoting developmental growth and independence of MR/DD persons. A move from institutional to community settings tends to result

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18/ U.S. Congress. Senate. Committee on Labor and Human Resources. Subcommittee on the Handicapped. Abuse of Institutionalized Handicapped Persons. Hearings, Apr. 1, 2, and 3, 1985.

in positive social adjustment and improved behavioral development for many disabled persons. 19/ However, for developmental growth to take place, according to research findings, the community setting must include certain essential features: effective teaching techniques, friendship networks for disabled persons and active involvement and positive attitudes of care providers. Some research has found that large institutions in which these features are present are also effective settings for developmental growth and that reducing the size of a facility does not necessarily change the daily pattern of care. 20/

Research indicates that there is great variation in community residential facilities. To provide as normal an environment as possible, community facilities need to be enriched with various therapeutic and rehabilitative programming. Studies have shown that clients in community care facilities benefit from increased interaction with qualified care providers within the community facility and from involvement in community activities and services outside the facility.

C. Service Settings and Costs of Residential Services for MR/DD Persons

Over the past 15 years, as MR/DD persons have been moving out of large public institutions into smaller private facilities, group homes or other community-based living arrangements, the cost of the ICF/MR program has been increasing.

19/ Conroy, James, et. al. A Matched Comparison of the Developmental Growth of Institutionalized and Deinstitutionalized Mentally Retarded Clients. American Journal of Mental Deficiency, v. 86, no. 6, 1982. p. 581-587.

20/ Selzer, Marsha, Ph.D. Known Effects of Environmental Characteristics on Resident Performance, LINKS, Bed. 1981.

Although the numbers of MR/DD persons served in public residential institutions decreased 42 percent between FY 1970 and FY 1984, from 189,546 to 109,827, the total number of residents in ICFs/MR rose steadily from the beginning of the ICF/MR program in 1972 until FY 1981 when the ICF/MR population peaked at 173,764. By FY 1984, the ICF/MR population had decreased 9 percent since the peak year, but the total Federal ICF/MR reimbursement increased by 40 percent from FY 1981 to FY 1984. However, part of this increase was due to changes in the cost of living, which increased 15.7 percent between FY 1981 and FY 1984. The average Federal ICF/MR per capita expenditure in FY 1981 was $10,553; this expenditure increased to $16,217 in FY 1984. 21/ (The average total ICF/MR per capita expenditure in FY 1984, State plus Federal, was $30,598.)

This increase in ICF/MR costs may be due to the increased expenditures required to bring facilities into compliance with standards and to the overhead required to maintain a large, comprehensive service facility. Even if the client population declines, staff of a large institution cannot be expected to decline proportionately because division of labor in a multi-service facility requires a large and diverse number of staff. Expenditures required to bring the facility into compliance with ICF/MR standards are prorated over time, and cannot be expected to decrease unless parts of the facility are sold, leased, or converted to another use. Therefore, even though MR/DD persons are increasingly placed in small, less expensive service settings, savings are difficult to obtain while the large, comprehensive institutions continue to be maintained.

21/ These expenditures are based on data presented in table 3.

Advocates for small, community-based facilities have stated that there is not sufficient public funding available for the expansion of community-based facilities while the large institutions absorb the major share of funds. This dilemma has led to legislative proposals requiring that public funding be reduced in large institutions and be made available in small, community-based facilities.

Although data show that public facilities are more costly than smaller, privately-operated facilities (see table 4), if staff salaries and benefits in private facilities were brought up to levels of State employees, this difference would be reduced. Also, if services were made more broadly available in the community, increased demand by persons not currently served could lead to increased overall costs. One mitigating factor, however, is that it could be less costly to provide community services to MR/DD persons who do not need the level of care provided in ICFs/MR. That is, some persons currently getting no community services may request some, but not all, of the services now made available in the ICFs/MR. Also, some residents of ICFs/MR may require fewer services than are required to be provided within the ICF/MR.

VII. LEGISLATIVE PROPOSALS

A. S. 873: The Community and Family Living Amendments of 1985

S. 873, introduced by Senator Chafee, would make Federal funds available in small community facilities while phasing out most Federal funding for institutions of more than 15 beds. Companion bills have been introduced in the House: H.R. 2523, introduced by Representative McDade, which is identical to S. 873, and H.R. 2902, introduced by Representative Florio, which includes minor differences.

These bills would encourage the development of community-based services for severely disabled individuals, and would severely reduce the amount of ICF/MR expenditures to be used for services in institutions after FY 2000. The balance of ICF/MR funding, with limited exceptions, could only be used for severely disabled individuals who resided in a family home or community living facility. Community living facilities could not exceed three times average family household size, or approximately nine persons. States would enter into agreements with the Secretary of HHS to reduce the number of disabled persons residing in facilities of more than nine beds. Beginning in FY 2000, the amount of Federal funding available for use in larger residential facilities would be limited to approximately 15 percent of the amount currently used. In addition, beginning in FY89, the Federal matching rate for services delivered in larger facilities would be progressively reduced.

The amendments would allow facilities of no more than 15 beds to continue to receive funding if they were in operation on September 30, 1985.

B. S. 1277 and H.R. 2863: Proposed Medicaid Home and Community-Based Services Improvement Act of 1985

S. 1277, introduced by Senator Bradley and H.R. 2863, introduced by Representative Wyden are identical bills that would give States the option of providing home and community-based services under Medicaid. This legislation would eliminate the current requirement that States obtain a waiver from the Secretary to deliver such services using Medicaid funds. Under this proposal, States would be authorized to deliver home and community-based services to persons who would otherwise require care in skilled nursing facilities and intermediate care facilities, the cost of which would be reimbursed under the State medicaid plan. This could include aged persons and persons with mental illness, mental retardation or physical disabilities who are eligible for Medicaid services.

C. S. 1948: Proposed Quality Services for Disabled Individuals Act of 1985

S. 1948, introduced by Senator Weicker, is intended to improve the quality of residential services for persons with developmental disabilities or mental illness and to authorize home and community-based services under the Medicaid program. This bill would establish a new Federal bureau to administer residential and community-based services funded under Medicare and Medicaid and to monitor the quality of these services.

A major provision of S. 1948 is that States would be required to include home and community-based services for the developmentally disabled as part of their State plan for use of Medicaid funds. Currently, such services are available only under the special waiver authority granted to the Secretary. Home and community-based services would be defined to include case management, homemaker or home health aide services, personal care including attendant care, adult day health services, habilitative and rehabilitative services, respite care (short-term residential care), and other approved services excluding room and board. States providing home and community-based services under Medicaid would be required to maintain at least their fiscal year 1985 level of State funding for such services, and current waiver authority would be repealed.

APPENDIX A. GLOSSARY OF ITEMS

Adult day care consists of a variety of health and social services provided to chronically ill or disabled individuals in a group setting and often includes general nursing, personal hygiene, recreational activities, counseling, transportation, and nutrition services.

Case management is commonly understood to be a system under which responsibility for locating, coordinating and monitoring a group of services for chronically ill or disabled persons rests with a designated person or organization.

Habilitation services are typically health and social services needed to insure optional functioning in activities of daily living of the mentally retarded or persons with related conditions.

Home health aide services included health-related services provided by a trained paraprofessional to persons unable to manage care for themselves or others in the home. Services generally consist of extension of therapy services, ambulation and exercise, assistance with medications, reporting changes in the patient's condition and needs and household services essential to the health care at home. These services are generally provided under the supervision of a registered nurse.

Homemaker services typically consist of general household activities (meal preparation and routine household care) provided by a trained homemaker when the individual regularly responsible for these activities is temporarily absent or unable to manage the home and care for himself/herself or others in the home.

Personal care services are those that assist functionally limited individuals with bathing, eating, dressing, toileting (generally referred to as "activities of daily living").

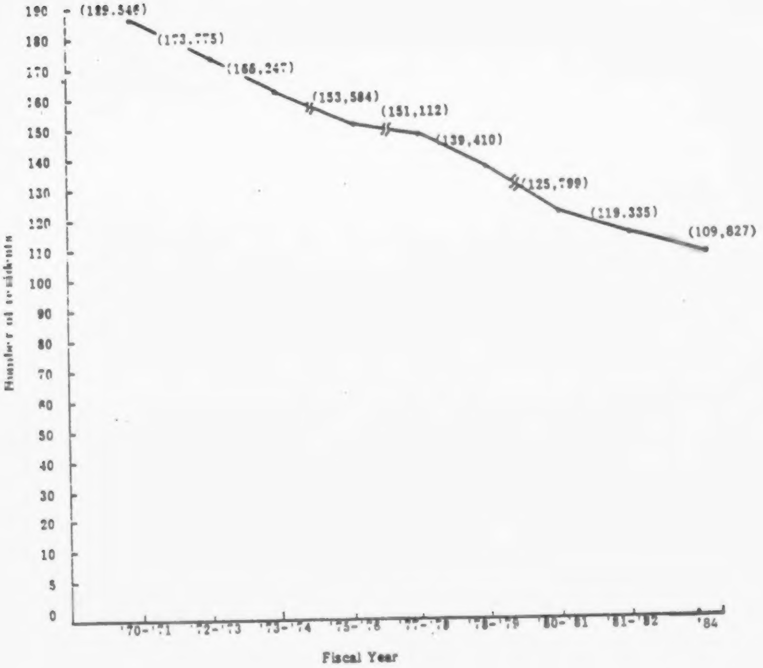
Prevocational services are those services needed to develop basic work habits and personal skills required for a disabled individual to take advantage of vocational rehabilitation services.

Respite care is short term care provided to individuals unable to care for themselves in order to provide relief for family or other persons normally providing the care. Respite care services may be provided in the individual's home or in an approved facility, such as a hospital, nursing home, foster home, or community residential facility.

Supported employment is competitive work in a setting with nondisabled persons for individuals with severe disabilities who require special supervision and assistance to perform the duties of the job.

Vocational rehabilitation services are provided to disabled persons to help make such persons employable. Services include physical and mental restoration, vocational training, special devices required for employment, job placement, and followup services.

APPENDIX B. AVERAGE DAILY POPULATION OF MENTALLY RETARDED PERSONS IN PUBLIC RESIDENTIAL FACILITIES: FY 1970-FY1984



Source: Table taken from Public Residential Facilities for the Mentally Retarded. 1982. Published by National Association of Superintendents of Public Residential Facilities for the Mentally Retarded. p. 4.

The 1984 number is from Public Expenditures for Mental Retardation and Developmental Disabilities in the U.S., Analytical Summary, by David Braddock, Ph.D., et al. University of Illinois at Chicago. p. 15.

APPENDIX C. PERCENT OF TOTAL PUBLIC AND PRIVATE RESIDENTIAL CARE FOR THE MENTALLY RETARDED IN MEDICAID-CERTIFIED ICF/MR BEDS, BY STATE: FY82

State	Percent
Minnesota	98.1%
Louisiana	95.9
Utah	88.8
Texas	88.6
Rhode Island	87.1
Virginia	85.1
Arkansas	83.8
Oregon	77.3
Alabama	75.6
Colorado	75.3
South Carolina	73.2
Georgia	72.8
Washington	72.3
Kansas	72.3
Indiana	70.6
Tennessee	67.4
Kentucky	67.2
Delaware	67.1
New Mexico	65.4
Illinois	64.0
North Carolina	63.0
Wisconsin	62.4
Nebraska	60.4
Mississippi	60.3
Oklahoma	59.9
South Dakota	59.3
Massachusetts	59.1
Nevada	58.1
Maryland	57.0
Idaho	56.0
Ohio	55.6
Pennsylvania	55.2
New Jersey	50.0
District of Columbia	49.2
Vermont	48.2
Alaska	47.6
Hawaii	45.2
California	44.8
Maine	43.0

APPENDIX C. PERCENT OF TOTAL PUBLIC AND PRIVATE RESIDENTIAL CARE SYSTEM FOR THE MENTALLY RETARDED IN MEDICAID-CERTIFIED ICF/MR BEDS, BY STATE: FY82--Continued

State	Percent
Montana	38.1%
Iowa	36.8
Michigan	36.0
New Hampshire	35.9
Connecticut	35.1
Missouri	30.0
Florida	26.4
New York	22.0
North Dakota	17.7
West Virginia	17.1
Arizona	---
Wyoming	---

Source: Lakin, Charles, Ph.D. Center for Residential and Community Services, University of Minnesota. From 1982 National Survey of Residential Facilities for Mentally Retarded People.

APPENDIX D: AVERAGE MEDICAID PAYMENT PER PATIENT DAY FOR ICF/MR SERVICES RANKED BY FY85 RATES

State	Per diem
District of Columbia	$145
Nevada	132
Massachusetts	126
Rhode Island	114
North Carolina	110
Georgia	107
Vermont	104
Florida	102
Pennsylvania	100
Maryland	99
Maine	98
Missouri	97
Kentucky	94
New Mexico	90
Arkansas	89
Iowa	89
Idaho	86
Colorado	85
Virginia	83
Nebraska	78
Oregon	78
Illinois	77
Tennessee	73
Minnesota	72
Ohio	70
Louisiana	68
South Dakota	64
Wisconsin	61
Michigan	52
Mississippi	49

APPENDIX D: AVERAGE MEDICAID PAYMENT PER PATIENT DAY
FOR ICF/MR SERVICES RANKED BY FY85 RATES--Continued

State	Per diem
California	$48
Texas	48
Indiana	44
West Virginia	41
Kansas	40
Oklahoma	40

Source: Health Care Financing Administration. Division of Medicaid Cost Estimates. Medicaid Program Characteristics Data. 1986. States not included in this table did not report data in time for inclusion in this table or did not participate in the ICF/MR program.

Senator **Durenberger**. The hearing will come to order.

Good morning, everyone. Today's hearing will take a close look at the Medicaid programs and the needs of developmentally disabled persons. This is a very complicated issue and it is also, I have learned over the years, an emotionally charged issue with which to deal.

The needs of developmentally disabled persons call forth our most important responsibility as policymakers. How we respond to those needs is a test of our society's character and its moral fiber.

In order to properly address the needs of these individuals, we have to, as they say, begin at the beginning and ask a number of very basic questions: How many developmentally disabled persons are there? What services are available to them through Federal and State and other programs? What services do they actually need and what is the setting in which these services are most appropriately delivered?

This last question takes us to what quickly becomes the heart of any discussion of Medicaid and the developmentally disabled, and that is the issue of institutional care versus community based services.

I feel strongly that today's hearing should not be reduced to an either/or situation, and we should not consider ourselves here to declare a preference for either institutions or community services; that kind of dichotomy, or polarization if you will, obscures the real issue. This is a lesson I have learned over several years now of having hearings with my colleague from Rhode Island on this subject here and in other parts of the country, including my home State.

So what is the issue? Simply this, that developmentally disabled persons have different needs which require different services and different settings. I believe the real challenge we face as policymakers is not to establish a preference for one setting over another but to adopt a policy which allocates resources appropriately along a continuum of services that the developmentally disabled need.

Does the Medicaid Program have a bias toward institutional care that is out of line with the needs of clients? Does that bias limit the expansion or the availability of community services that might be more desirable and effective for some developmentally disabled persons? What can be done to remove existing biases and to instead promote the availability of community services without restricting the availability of institutional care for those who really need it?

These are the kinds of questions we have been asking ourselves now for several years, and we will continue to ask and we will ask at this hearing.

I have a statement here from the Minnesota Coalition of Parents and Friends for Community Residential Services, prepared by my long-time, very good friend, Galen Pate, the courageous father of a young woman with multiple disabilities. I would like to share a part of Galen's statement with you because I believe it represents the view and the experience of a lot of concerned parents and family members.

Galen's daughter, Elizabeth, has been diagnosed as having cerebral palsy, profound mental retardation and a seizure disorder. Because of the level of care that his daughter requires, Galen was not able to care for her in his home. Because he wanted to be closely involved in his daughter's development, he began working with other families in his community to develop a group home. His original desire was to set up a small home for about six people, but in the early stages of planning it became evident that the cost for meeting the needs of profoundly handicapped persons would require a home designed on a larger scale with a higher staffing ratio and more costly physical plant requirements.

While he still is involved as ever in Betsy's life—and that is his life—his experience has tempered his earlier feelings about what type of setting would provide Betsy with the best care.

Galen and other members of the Minnesota Coalition of Parents and Friends for Community Residential Services have worked hard to develop community residential facilities, but their experience has shown that other kinds of facilities are also needed, particularly for those individuals who are severely and profoundly retarded, medically fragile, or in need of significant behavior management.

It is possible that Galen's group speaks for many when it says the system needs to be expanded in a planned and thoughtful manner so that the quality of care currently available to our children is not compromised through a rush to reduce the size of the facility or the size of the Federal Medicaid budget.

The range of service options needs to be expanded, not limited, so that our children and all other children who will likely follow them continue to have an effective array of choices available. That is the end of his quote.

I wanted to share that statement with you becuase I know that this is an emotionally charged issue; that many people here today have loved ones whose very lives are on the line when we sit here and talk about changes in Federal programs.

So to you, let me say that I have heard and understand your concerns, the concerns of devoted parents and supportive family members.

I, for one, am not approaching today's hearings with any preconceptions as to the outcomes it should produce. I simply believe that it is time to ask some very basic questions: How can Federal programs best insure that the developmentally disabled receive highest quality services in a way which maximizes their freedom, their safety, and their individual potential to learn and to grow?

We have a long list of witnesses today. We have tried to accommodate as many different areas of expertise as possible. In order to hear from everyone and to have time for questions, we are going to have to adhere strictly to our 5-minute rule. So I will ask all of our witnesses to be brief, with the understanding that your full statements will made part of the record. Amplifying statements can be made part of the record up to a certain reasonable period of time after the conclusion of this hearing. We don't want anyone to be denied the opportunity to add their experiences, even from the last hearing we have had on this subject, to this issue.

So let us now proceed with our first panel. But I will yield, first, to my colleague, Senator Chafee.

Senator CHAFEE. Well thank you very much, Mr. Chairman. And I would like to join in welcoming our distinguished colleague, Senator Weicker, and those witnesses who are going to testify today, and express my appreciation to them, and to you, Mr. Chairman, for holding this hearing.

Today's hearing focuses on the Medicaid Program and its impact on long-term care services for those with developmental disabilities. Through the testimony of researchers, the Department of Health and Human Services, State policymakers, labor union representatives, and national organizations representing those with disabilities, we will have a chance to examine the current Medicaid Program and determine, or have light shed upon whether it is responsive to the needs of those with disabilities.

This is an issue, as you know, Mr. Chairman, that I have devoted a great deal of time to over the past 5 years. And I thank you for your cooperation. As you mentioned, we have held several hearings, including one in your own State, a couple of years ago.

It is a topic of critical importance to hundreds of thousands of people throughout our country, and one that deserves our attention, and immediate attention.

I expect that this hearing will give us an idea of what the future holds if there are no changes in the current program. In other words, we are trying to ascertain how is the current Medicaid Program working in dealing with this particular group of individuals? And I hope that it will help us better to focus our vision for the future.

Now as you know, I have proposed a reform package for the Medicare Program, S. 873, known as the Community and Family Living Amendments of 1983. It is a package I expect to refine and revise in the coming months. That is the purpose of the hearings we have held and the hearing today. The hearing today will help serve as a basis for information used in the process for refinement of S. 873.

Since I first began examining the Medicaid Program's treatment of long-term care services for the developmentally disabled, I have become firmly convinced that this program is in desperate need of reform.

I think it is important to remember how Medicaid developed. It is the sole Federal program which provides States with funding for the long-term care services for the disabled. It began as a program for medical assistance for low-income individuals. It is a medical program. In time, the program was used to pay for long-term care services for the elderly and for the disabled. Today, more than half the funds from Medicaid are used for this purpose; that is, long-term care services for the elderly and for the disabled. But the long-term care services that the program will pay for are still routed in a medical model. In other words, it is based on medical need.

As our understanding of the capabilities and the needs of individuals with disabilities has progressed—and indeed it has progressed remarkably over the past several years—it has become clear that the traditionally medically oriented long-term care services provided through Medicaid are often inappropriate for those with developmental disabilities. In other words, the needs of this group is not strictly medical.

I have received letters from individuals, from States, from organizations, across the country describing the problems with the present program. Parents whose disabled children are currently in school due to the enactment of the Education for All Handicapped Children's Act, which, of course, Senator Weicker was so instrumental in having passed, these parents fear that when their children become 18 or 21 there will be no appropriate services available. That is known as the aging out problem. Parents who are desperately trying to care for their children at home, without assistance by the State or Federal Government, are telling me they are becoming burned out, just exhausted, from their efforts to care for their children at home, and must, in many instances, against their wishes, place their children outside the home because there is no place else they receive no other assistance through any Federal program.

Individuals with cerebral palsy, spinal cord injury, and traumatic brain injury write to tell me that they are forced to live in nursing homes rather than in their own community because the Medicaid Program is misdirected. These are individuals who could be productive members of the community with a small amount of support.

Now States which are moving toward a system of care in which the primary consideration is the needs of each individual write to tell me they are frustrated in their efforts to do this because of lack of flexibility in the Medicaid Program, and that is the so-called waiver provision which we will hear about.

It seems to me that it makes little sense to pour billions of dollars into a program which results in increased dependency which encourages out-of-home placements and discourages progress. And how can it be so difficult to adopt a Medicaid Program to the needs of those who require its assistance?

Now I have read the testimony to be presented here today with great interest. There are many ideas which deserve this committee's serious consideration. Now that we have accomplished the complicated task of tax reform—which, of course, required an enormous amount of this committee's time this year—perhaps we will have an opportunity during the next session of Congress to attack the equally difficult task to reforming the Medicaid Program.

Now one goal in accomplishing that reform would be to open opportunities to individuals with disabilities; to extend the values of freedom of work, of family living, to those with physical and mental impairments.

The basic premise of any reform should be that a full range of service—and this is what the chairman touched on—and options be available, and that the funding should flow toward individual needs. And that is what we will seek to do as we proceed with not only these hearings but with S. 873, the Community Living and Family Act.

So thank you very much, Mr. Chairman, for holding this hearing.

Senator DURENBERGER. John, thank you for your leadership and your constant reminder on this committee of our needs to take on the most difficult problems. And I understand that from time to time you make a statement that includes the fact that you are open to change and all that sort of thing. That is because you have taken on a very controversial subject and you are to be complimented for that.

I guess our first witness today is never found in any issue that doesn't have some controversy connected with it, and today he has gone to the ultimate end to demonstrate his own sense of disability. Lowell Weicker, a Senator from Connecticut, comes to us with a background of almost total commitment to the disadvantaged in our society, and particularly those who suffer from birth or from accidents or illness during the course of their lives with physical and medical impairments. And I guess there is nobody that I have ever served with in this body that has more represented to me the role of policymaker on behalf of those who are substantially dependent on society's policy response to their needs than Lowell Weicker. So we are very, very pleased that he has asked to be the first witness at this hearing.

And, Lowell, your full statement will be made part of the record. And, without being instructed, you may do as you please. [Laughter.]

STATEMENT OF HON. LOWELL P. WEICKER, JR., A U.S. SENATOR FROM THE STATE OF CONNECTICUT

Senator **Weicker**. Thank you very much, Mr. Chairman. I want to thank you for taking the time to hold the hearings on these important subjects. Indeed, in terms of the Finance Committee, you are Mr. Health on those issues that affect so many Americans in so many different ways, including the ones before us today.

John Chafee, John, who has devoted a good portion of his career to finding the answers toward advancing the state of the art when it comes to our mentally and physically disabled, and he has been the driving force to get away from the customs of the past and keep pushing us into the future.

This is a great day, I have to say, Mr. Chairman, parenthetically. You have been so interested in so many issues of health. It is a great day specifically in the sense of the subject matter before us, in that yesterday, it is my understanding that the House of Representatives passed out of committee 33 to 0 the reauthorization of Public Law 94-142, with many of the changes—bringing the coverage period back to birth; closing some of the loopholes. It might take a little longer than we anticipated in the Senate bill, but basically we are in agreement on changing the state of the art as it comes to the education of the handicapped. I suspect that bill is going to be passed in this session, and to that extent, it is a great day.

The other reason why it is a great day has nothing specifically to do with this hearing. While this hearing is going on, downtown at the Health and Human Services the announcement is being made that the second great breakthrough—the first being the identification of the cloning of the virus—the second great breakthrough as to AIDS has taken place; specifically, that a drug has come on the scene which holds promise for the extension of life. It is not a cure. What the extension is, no one knows. There are side effects. But for the first time there is something that the National Institutes of Health deems should be made available for public use, or, more particularly, those 10,000 to 12,000 that are now dying. And I think that if anybody wonders, is your money well spent at the National

Institutes of Health—and I also want to give a credit and a bow to the Burroughs Welcome Co. who has worked with the National Institutes of Health—today should dispel any such doubt. It is a great day for medical history in the United States.

And I want to thank you again for the opportunity to present my views on the matters before you.

Ten years ago, Congress enacted a landmark piece of civil rights legislation, known as Public Law 94-142, and basically what that did was to prevent schools from closing their doors to handicapped students.

With a Federal mandate entitling every handicapped student to an education with the least restrictive environment, commonly known as "mainstreaming," the school house doors were opened, and they were opened in such a fashion that—yes, I can assure everyone here to put it in very succinct and practical terms—none of you have to worry about paying for my child, Sonny. The education system in the United States is such that when he gets to be of age he will be out there making his own living, and indeed living his own life. That is exactly what Public Law 94-142 was meant to do.

However, 15 years ago the Congress created another program, which unfortunately took us in the opposite direction of Public Law 94-142, the ICF/MR program. And the intention of ICF/MR, intermediate care facility for the mentally retarded program, was to provide quality services to developmentally disabled persons, with no mandate for mainstreaming, or at least restrictive environment. The ICF/MR funding went primarily to existing state institutions. And these, for the most part, are large, isolated, congregate care settings.

It is not only a costly program, with an average annual cost per client between $25,000 and $40,000 in 1984, it is a poor quality one.

Now I am going to skip over the next several pages of my testimony because that testimony is made available to your committee as to exactly what that care consists of.

I wish you could have sat with me, to sum it all up, and heard the individual tales of horror that go on in your country—my country, our country—as to how these people get treated. Believe me, there is something wrong with a system that is paying money for their care, and the care that they get is such that it is, in many instances, life terminating; in all instances, life threatening.

Now the objective of that investigative effort was not to encourage the use of institutions by forcing certain repairs or adjustments, although I have heard that accusation stated, we sought to educate the American public to make this Nation understand that institutions remain a hidden reality for many and an omnibus possibility for all too many.

Mr. Chairman, I have pushed hard for several pieces of legislation to address the problems we discovered in our investigation. We have increased the number of surveyors at the Health Care Financing Administration to beef up quality assurance. We have required that many of those surveyors be trained specialists in developmental disabilities. These changes have had an impact on the lives of institutional residents already.

The 464 Federal surveys conducted by the Health Care Financing Administration between March and September of 1985, the new guidelines for conducting those surveys, States are now beginning to focus more on the client rather than paperwork compliance. More plans of correction are being implemented and more citations for deficiencies are being issued. That is only a baby step in the right direction.

We were also recently successful in enacting legislation to expand protection in advocacy services for the mentally ill persons in institutions. As you know, that bill is now law; that the mentally ill have advocacy, not just the mentally retarded.

And then we have introduced 1984, which really comes to the matter of your committee, the Quality Services For Disabled Persons Act, which is pending before this committee.

All Americans need to understand how far short the Nation has fallen from fulfilling the vow made by President Kennedy 25 years ago. Reliance on the cold mercy of custodial isolation will be supplanted by the open warmth community concern.

I believe that changes in the current system of Medicaid funding for disabled persons are critical to improving the lives of these individuals.

The mentally disabled of this generation need some mechanism to assure delivery of quality services. They need a system to monitor the provision of these services, and they need incentives for government to expand home and community based services.

Let me go back to Public Law 94-142 for a moment. I dwell on this legislation because I think it represents Federal legislation at its best. This law has sent a signal to the Nation that handicapped persons have a right to the same opportunities as their nonhandicapped peers; the opportunity to develop their potential to its maximum; the opportunity to participate in the mainstream of American life; and the opportunity for choices and independence.

The Medicaid ICF/MR Program sends the opposite signal. This program, by everyone's assessment, is institutionally biased; that, at best, it funds sheltered and limited opportunities and custodial care; and that, at worst, it promotes segregation, dependence, and isolation.

And while there is a great difference of opinion about how many, if any, of our developmentally disabled citizens would require institutionalization if adequate community alternatives were available, there is no difference of opinion about the state of the art and the most effective services for these citizens.

We know that persons who were once written off as hopeless now function as productive members of society; people who have the satisfaction and enhance self-concept that comes from bringing home a pay check, and being a taxpayer rather than a tax user. We know that the limitations placed on these people are our limitations created through limited opportunities for education and training. Our goal should be to mainstream all of our developmentally disabled citizens and we are moving toward the goal of mainstreaming everyone with Public Law 94-142, and we need to establish that goal with Medicaid services.

S. 1948, the bill I introduced last year, attempts to assure both quality services for those in our institutions and to promote the expansion of community alternatives.

Now let me just say this, Mr. Chairman, as we conclude. John Chafee and I have both been through this grinder of those who have loved ones in the institutions, those who have loved ones that they feel should be in the mainstream, in community settings. The state of the art has changed. It hasn't been the fault of the parents who neglected their children or their friends. They took advantage of the best advice in the state of the art 25, 30, 40 years ago, and that was the institution. There is no reason why society should penalize them today. They should have our understanding and the best of our minds to assisting them in their problem. But the state of the art has changed and institutionalization is not the way to go. The way to go is in the community setting with an entirely different approach as to what that individual can do.

That's the fine line that both John and myself have to walk.

Parents of those that have their children in institutions, they don't want to be neglected or feel that all of a sudden the problem is in their lap while others want state of the art today, and they should have it.

So I would hope that what you craft in the sense of your legislation will take into account both of these matters. Make no doubt about it where the emphasis has to go. It cannot go to a past state of the art but that of the future. And I would hope in that regard that your committee would act on that promptly and would do its best as I know it will, with the chairman's heart and mind and what he has done today for so many others, that we would now be getting on to resolving these particular problems as they relate to this matter.

Senator DURENBERGER. Well thank you very much for that testimony, and particularly for the last 2 minutes. I cannot think of a better summary of the present situation that we find ourselves in. And it reminded me of the feeling I've had through several years of sitting here, with the responsibility of majority, in dealing with the political institutional arrangements with which we have to operate—that is, a 1935 Social Security Act, amended periodically over time, to reflect just what you talked about, changes and differences, not only in care giving but in advocacy and some other things.

So I look back periodically on these 20 titles, and I say, oh, God, that doesn't look like 1986. You know, it looks like—a little bit of it looks like 1935, a little bit of it looks like 1965, you know. We need to get in there and turn that thing on its head. And if we are talking about the Social Security of this society, we really ought to be looking at that in the light of 1986 and beyond without neglecting, as you have indicated, those who, for a variety of reasons, have come into this system in the 1930's and the 1960's and everything else. And so I really appreciate that, personally, as one who has some responsibility as a subcommittee chair, dealing with an issue that others have put a lot more personal time into. The two of you are the leaders in that area.

I appreciate that statement as putting your finger right on the pulse of what we need to do.

John?

Senator CHAFEE. Well thank you, Mr. Chairman.

I want to thank Senator Weicker for coming here. He is a powerful advocate. And I learned long ago, if you want to be in a scrap around this place, try and get Lowell Weicker on your side. No one has ever accused him of masquerading his intentions or his position. You know where he stands. He comes on vigorously, powerfully, eloquently, and with excellent reasoning supporting him, his position. So, Lowell, thank you very much for coming.

Senator Weicker. Thank you.

Senator Chafee. And we look forward to working with you in the days ahead on this.

This thing isn't going to be solved today or tomorrow or this calendar year, but we will prevail in the end, I am confident.

Senator Weicker. I know you will. And I thank you both very much.

Senator Durenberger. Thank you, Lowell.

Our first panel—we may call it our first two witnesses, appropriately—are Glenn Hackbarth, the Deputy Administrator of the Health Care Financing Administration; and Carolyn Gray, who is Acting Deputy Assistant Secretary of the Office of Human Developmental Services in HHS.

I understand Carolyn is here at least, in part, because Dr. Jean Elder, who is Acting Assistant Secretary, got sent out to Illinois today by the Secretary, and since we had such a raft for some reason of Minnesotans here today, I was hopeful we would add one more in Jean Elder. [Laughter.] But we welcome both of you.

Senator Chafee. Mr. Chairman, I have studied the testimony and I will be right back. I just received a call that I have just got to return. So I will be right back.

Senator Durenberger. All right.

May I say to both of you that your statements, as you know, are part of the record, and you may proceed to summarize them. We will start with Glenn.

[The prepared written statement of Senator Weicker follows:]

TESTIMONY OF SENATOR LOWELL WEICKER JR.
ON MEDICAID SERVICES FOR DEVELOPMENTALLLY DISABLED PERSONS
SEPTEMBER 19, 1986

THANK YOU FOR THIS OPPORTUNITY TO PRESENT MY VIEWS REGARDING MEDICAID FINANCING OF SERVICES TO DEVELOPMENTALLY DISABLED PERSONS. FOR MORE THAN THREE YEARS I HAVE EXAMINED THESE PROGRAMS AND MY CONCLUSION IS THAT THEY ARE IN GREAT NEED OF CHANGE AND IMPROVEMENT.

TEN YEARS AGO CONGRESS ENACTED A LANDMARK PIECE OF CIVIL RIGHTS LEGISLATION KNOWN AS PUBLIC LAW 94-142, THE EDUCATION FOR ALL HANDICAPPED CHILDREN ACT. THAT LEGISLATION WAS THE BEGINNING OF THE END OF AN ERA OF SEGREGATION AND DISCRIMINATION AGAINST HANDICAPPED CHILDREN IN OUR SCHOOLS. NO LONGER COULD SCHOOLS CLOSE THEIR DOORS TO HANDICAPPED STUDENTS AND SAY, "YOU LOOK DIFFERENT FROM THE OTHERS, GO AWAY," OR "YOU DON'T LEARN THE WAY THE OTHERS DO, GO AWAY."

WITH A FEDERAL MANDATE ENTITLING EVERY HANDICAPPED STUDENT TO AN EDUCATION IN THE LEAST RESTRICTIVE ENVIRONMENT, COMMONLY KNOWN AS MAINSTREAMING, THE SCHOOL HOUSE DOORS WERE OPENED. PUBLIC EDUCATION NOW SERVES OVER 4 MILLION STUDENTS WITH HANDICAPPING CONDITIONS RANGING FROM MILD LEARNING DISABILITIES TO SEVERE RETARDATION. THE BENEFITS TO BOTH HANDICAPPED STUDENTS AND THEIR FAMILIES AND TO OUR SOCIETY AS A WHOLE FAR OUTWEIGH THE FEDERAL INVESTMENT OF OVER 1 BILLION DOLLARS A YEAR.

AN INVESTMENT IN SCHOOLING FOR HANDICAPPED CHILDREN MEANS THE DIFFERENCE BETWEEN DEPENDENCE AND INDEPENDENCE THROUGHOUT LIFE. IT MEANS A TAX PAYER RATHER THAN A TAX USER. IT MEANS A CONTRIBUTOR TO SOCIETY RATHER THAN A DRAIN ON SOCIETY.

FIFTEEN YEARS AGO THE CONGRESS CREATED ANOTHER PROGRAM WHICH, UNFORTUNATELY TOOK US IN THE OPPOSITE DIRECTION OF P.L. 94-142: THE ICF/MR PROGRAM. THE INTENTION OF THE ICF/MR, OR INTERMEDIATE CARE FACILITY FOR THE MENTALLY RETARDED PROGRAM, WAS TO PROVIDE QUALITY SERVICES TO DEVELOPMENTALLY DISABLED PERSONS. WITH NO MANDATE FOR MAINSTREAMING, OR LEAST RESTRICTIVE ENVIRONMENT, THE ICF/MR FUNDING WENT PRIMARILY TO EXISTING STATE INSTITUTIONS. THESE, FOR THE MOST PART, ARE LARGE, ISOLATED CONGREGATE CARE SETTINGS.

NOT ONLY IS THIS ICF/MR PROGRAM A COSTLY ONE WITH AN AVERAGE ANNUAL COST PER CLIENT BETWEEN $25,000 AND $40,000 IN 1984, IT IS A POOR QUALITY ONE. AS CHAIRMAN OF THE SUBCOMMITTEE ON THE HANDICAPPED I HAVE CHAIRED FIVE DAYS OF HEARINGS AND CONDUCTED

TWO MAJOR INVESTIGATIONS INTO CONDITIONS IN INSTITUTIONS FOR THE DISABLED OVER THE LAST THREE YEARS. MY STAFF HAS VISITED OVER 50 INSTITUTIONS ACROSS THE COUNTRY AND INTERVIEWED OVER 700 PEOPLE. I HAVE HEARD TESTIMONY FROM PARENTS, RESIDENTS OF INSTITUTIONS, ADMINISTRATORS OF FACILITIES, ADVOCATES, AND STATE AND FEDERAL OFFICIALS.

FROM THE HEARINGS, THE INVESTIGATIONS, AND THE MANY WITNESSES PROVIDING TESTIMONY, ONE FACT WAS PAINFULLY EVIDENT: THE SYSTEM SET UP BY OUR FEDERAL GOVERNMENT TO FUND THESE INSTITUTIONS IS NOT WORKING.

IT IS NOT WORKING WHEN WHAT SHOULD BE QUALITY SERVICES, PROVIDED IN THE FORM OF ACTIVE TREATMENT TO DISABLED RESIDENTS, EXIST LARGELY ON PAPER.

IT IS NOT WORKING WHEN THERE IS MINIMAL PROTECTION FROM NEGLECTFUL AND ABUSIVE CONDITIONS.

IT IS NOT WORKING WHEN THE FEDERAL GOVERNMENT POURS BILLIONS OF DOLLARS INTO BRICKS AND MORTAR AND TURNS ITS BACK ON THE QUALITY OF SERVICES.

MR. CHAIRMAN, I HEARD FROM MANY PARENTS AND RESIDENTS OF INSTITUTIONS DURING MY HEARINGS.

I HEARD FROM WILBUR SAVIDGE, WHOSE SON WENT INTO A STATE FACILITY FOR THE RETARDED WITH THE ABILITY TO WALK AND FEED HIMSELF. FOUR YEARS LATER HE COULD DO NEITHER. IN THOSE SAME 4 YEARS, YOUNG JONATHAN SAVIDGE WAS INJURED A TOTAL OF 124 TIMES.

AND THERE WAS THE STORY OF "AUGIE", INSTITUTIONALIZED FOR 44 YEARS IN A STATE FACILITY, THE LAST 3 YEARS IN A SHOWER STALL WITH NOTHING BUT A THIN COTTON SHEET BETWEEN HIS NAKED BODY AND THE TILE FLOOR.

AND THERE WAS 14 YEAR OLD CHRIS COCHERHAM, WHOSE PARENTS WERE ABLE TO CAPTURE ON FILM THE SCARS AND BRUISES OF DOZENS OF SEPARATE ACTS OF VIOLENCE AND ABUSE.

AS A U.S. SENATOR I WAS OUTRAGED THAT FACILITIES WHERE THIS BRUTAL ABUSE TOOK PLACE WERE CERTIFIED BY THE FEDERAL GOVERNMENT TO RECEIVE MILLIONS OF FEDERAL DOLLARS PER YEAR.

I WAS ALSO ASHAMED WHEN JOHATHAN SAVIDGE'S FATHER LOOKED ME IN THE EYE AND ASKED ME "WHY DOES THE FEDERAL GOVERNMENT ALLOW THESE ATROCITIES TO GO UNCHECKED?"

MR. CHAIRMAN, I WOULD BE HAPPY TO MAKE THE COMPLETE RECORDS FROM MY STAFF'S INVESTIGATION AND FROM THE HEARINGS AVAILABLE TO YOU AND YOUR STAFF AS YOU CONSIDER WHAT CHANGES TO MAKE IN THIS PROGRAM.

THE OBJECTIVE OF MY INVESTIGATIVE EFFORT WAS NOT TO ENCOURAGE USE OF INSTITUTIONS BY FORCING CERTAIN REPAIRS OR ADJUSTMENTS, ALTHOUGH I'VE HEARD THAT ACCUSATION. INSTEAD, WE SOUGHT TO EDUCATE THE AMERICAN PUBLIC, TO MAKE THIS NATION UNDERSTAND THAT INSTITUTIONS REMAIN A HIDDEN REALITY FOR MANY AND AN OMINOUS POSSIBILITY FOR ALL TOO MANY.

MR. CHAIRMAN, I HAVE PUSHED HARD FOR SEVERAL PIECES OF LEGISLATION TO ADDRESS THE PROBLEMS WE DISCOVERED IN OUR INVESTIGATION. WE HAVE INCREASED THE NUMBER OF SURVEYORS AT THE HEALTH CARE FINANCING ADMINISTRATION TO BEEF UP QUALITY ASSURANCE. WE HAVE REQUIRED THAT MANY OF THOSE SURVEYORS BE TRAINED SPECIALISTS IN DEVELOPMENTAL DISABILITIES. THESE CHANGES HAVE HAD AN IMPACT ON THE LIVES OF INSTITUTIONAL RESIDENTS ALREADY. WITH 444 FEDERAL SURVEYS CONDUCTED BY THE HEALTH CARE FINANCING ADMINISTRATION BETWEEN MARCH AND SEPTEMBER OF 1985, AND NEW GUIDELINES FOR CONDUCTING THOSE SURVEYS, STATES ARE NOW BEGINNING TO FOCUS MORE ON THE CLIENT RATHER THAN ON PAPERWORK COMPLIANCE. MORE PLANS OF CORRECTION ARE BEING IMPLEMENTED AND

MORE CITATIONS FOR DEFICIENCIES ARE BEING ISSUED. WE HAVE TAKEN A BABY STEP IN THE RIGHT DIRECTION, BUT LET ME EMPHASIZE THAT IT IS ONLY A BEGINNING.

WE WERE ALSO RECENTLY SUCCESSFUL IN ENACTING LEGISLATION TO EXPAND PROTECTION AND ADVOCACY SERVICES FOR MENTALLY ILL PERSONS IN INSTITUTIONS. AND I HAVE INTRODUCED S. 1948, THE QUALITY SERVICES FOR DISABLED PERSONS ACT, WHICH IS PENDING BEFORE THIS COMMITTEE.

ALL AMERICANS NEED TO UNDERSTAND HOW FAR SHORT THE NATION HAS FALLEN FROM FULFILLING THE VOW MADE BY PRESIDENT KENNEDY 25 YEARS AGO THAT "RELIANCE ON THE COLD MERCY OF CUSTODIAL ISOLATION WILL BE SUPPLANTED BY THE OPEN WARMTH OF COMMUNITY CONCERN."

I BELIEVE THAT CHANGES IN THE CURRENT SYSTEM OF MEDICAID FUNDING FOR DISABLED PERSONS ARE CRITICAL TO IMPROVING THE LIVES OF THESE INDIVIDUALS.

THE MENTALLY DISABLED OF THIS GENERATION NEED SOME MECHANISM TO ASSURE DELIVERY OF QUALITY SERVICES, THEY NEED A SYSTEM TO MONITOR THE PROVISION OF THESE SERVICES, AND THEY NEED INCENTIVES FOR GOVERNMENT TO EXPAND HOME AND COMMUNITY BASED SERVICES.

LET ME GO BACK TO THE EDUCATION FOR ALL HANDICAPPED CHILDREN ACT FOR A MOMENT. I DWELL ON THIS LEGISLATION BECAUSE I THINK IT REPRESENTS FEDERAL LEGISLATION AT ITS BEST. THIS LAW HAS SENT A SIGNAL TO THE NATION THAT HANDICAPPED PERSONS HAVE A RIGHT TO THE SAME OPPORTUNITY AS THEIR NON-HANDICAPPED PEERS: THE OPPORTUNITY TO DEVELOP THEIR POTENTIAL TO ITS MAXIMUM, THE OPPORTUNITY TO PARTICIPATE IN THE MAINSTREAM OF AMERICAN LIFE, THE OPPORTUNITY FOR CHOICES AND INDEPENDENCE.

THE MEDICAID ICF/MR PROGRAM SENDS THE OPPOSITE SIGNAL. THE ICF/MR PROGRAM, BY EVERYONE'S ASSESSMENT, IS INSTITUTIONALLY BIASED. AT ITS BEST, IT FUNDS SHELTERED AND LIMITED OPPORTUNITIES AND CUSTODIAL CARE. AT ITS WORST IT PROMOTES SEGREGATION, DEPENDENCE AND ISOLATION. WHILE THERE IS A GREAT DIFFERENCE OF OPINION ABOUT HOW MANY, IF ANY, OF OUR DEVELOPMENTALLY DISABLED CITIZENS WOULD REQUIRE INSTITUTIONALIZATION IF ADEQUATE COMMUNITY ALTERNATIVES WERE AVAILABLE, THERE IS NO DIFFERENCE OF OPINION ABOUT THE STATE OF THE ART AND THE MOST EFFECTIVE SERVICES FOR THESE CITIZENS.

WE KNOW THAT PERSONS WHO WERE ONCE WRITTEN OFF AS HOPELESS NOW FUNCTION AS PRODUCTIVE MEMBERS OF SOCIETY; PEOPLE WHO HAVE THE SATISFACTION AND ENHANCED SELF-CONCEPT THAT COMES FROM BRINGING HOME A PAYCHECK, FROM BEING A TAX PAYER RATHER THAN A TAX USER. WE KNOW THAT THE LIMITATIONS PLACED ON THESE PEOPLE ARE OUR LIMITATIONS, CREATED THROUGH LIMITED OPPORTUNITIES FOR EDUCATION AND TRAINING.

OUR GOAL SHOULD BE TO MAINSTREAM ALL OF OUR DEVELOPMENTALLY DISABLED CITIZENS. WE ARE MOVING TOWARDS THE GOAL OF MAINSTREAMING EVERYONE WITH P.L. 94-142, AND WE NEED TO ESTABLISH THAT GOAL WITH MEDICAID SERVICES.

S. 1948, THE BILL I INTRODUCED LAST YEAR, ATTEMPTS TO BOTH ASSURE QUALITY SERVICES FOR THOSE IN OUR INSTITUTIONS AND PROMOTE THE EXPANSION OF COMMUNITY ALTERNATIVES. P.L. 94-142 DOES NOT REQUIRE THAT EVERY SINGLE DISABLED PERSON BE IN A REGULAR CLASSROOM, BUT IT DOES HOLD OUT THAT GOAL. S. 1948 DOES THE SAME THING BY ESTABLISHING INDEPENDENCE, PRODUCTIVITY AND INTEGRATION INTO THE COMMUNITY AS PRINCIPLES UPON WHICH PLACEMENT AND SERVICE DECISIONS ARE MADE. FURTHER IT REQUIRES EVERY STATE THAT PARTICIPATES IN THE INSTITUTIONAL ASPECT OF THE PROGRAM TO ALSO PARTICIPATE IN THE COMMUNITY SERVICES ASPECT OF THE PROGRAM.

UNTIL WE SEND ONE CLEAR MESSAGE TO THE STATES THAT WE WANT ALL OF OUR HANDICAPPED CITIZENS, WHETHER YOUNG, OLD, SEVERELY, OR MILDLY DISABLED, AS PART OF THE MAINSTREAM, WE WILL CONTINUE TO FOSTER SEGREGATION, DISCRIMINATION, AND DEPENDENCE.

I COMPLIMENT THIS COMMITTEE FOR TAKING THE TIME TO CAREFULLY EXAMINE THIS IMPORTANT ISSUE AND I URGE YOU TO CONSIDER THE PROVISIONS IN S. 1948, WHICH WOULD GO A LONG WAY TOWARDS IMPROVING THE LIVES OF OUR DEVELOPMENTALLY DISABLED CITIZENS.

THANK YOU.

STATEMENT OF GLENN HACKBARTH, DEPUTY ADMINISTRATOR, HEALTH CARE FINANCING ADMINISTRATION, WASHINGTON, DC

Mr. **Hackbarth**. Thank you, Mr. Chairman.

I am pleased to be here today to discuss the Health Care Financing Administration's commitment to serving the mentally retarded and other developmentally disabled persons. To [illegible]e stage for today's hearing, I will describe the role that Medicaid plays in financing those services.

As you know, federally assisted programs are now the major source of financing for services for the retarded and developmentally disabled. Amendments to the Social Security Act and other entitlement programs, including Medicaid, have created a diverse set of benefits for persons with developmental disabilities.

Most mentally retarded and other developmentally disabled persons become eligible for Medicaid through a determination of disability under the Supplemental Security Income Program. Once eligible, the individual is entitled to the full range of regularly provided Medicaid services in a State.

In addition to the mandatory services covered under Medicaid, States may also cover care in ICF's/MR. In addition, States may provide, under a home and community based waiver, services not normally covered by Medicaid, and those services may be targeted to individuals with developmental disabilities.

As you know, when Medicaid optional coverage of ICF/MR was enacted in 1971, the purpose was to provide explicit Medicaid coverage for the mentally retarded persons with related conditions living in institutions. ICF/MR services were covered when an eligible recipient requires and receives active treatment in a facility meeting all the standards prescribed by law and regulation. The active treatment requirement was added in order to avoid the continuation of a long history of custodial care for retarded persons.

When the ICF/MR benefit was first instituted, most of the participating facilities were quite large and most of them were public institutions. However, over the last decade there have been increasing numbers of small facilities added to the program. And at this point in time, roughly 75 percent of the facilities participating have 15 or fewer beds. Only 3 percent are large institutions with more than 300 beds. Most of those very large institutions are state institutions.

As of 1982, 80 percent of the clients living in public facilities were functioning within the severe and profound range of mental retardation, while 66 percent of the clients in the smaller facilities were functioning in the mild to moderate range of retardation.

Large public facilities for the mentally retarded are now serving the most severely disabled persons in our society while smaller, privately operated, community-based facilities tend to serve the less disabled persons.

As you know, under the Omnibus Reconciliation Act of 1981, the Secretary was authorized to waive certain Medicaid requirements. This is the so-called home and community based waiver program. Under these waivers, States may provide a variety of home and community based services to recipients who would otherwise be institutionalized or be at risk of institutionalization.

In order to obtain a waiver, a State must demonstrate that the cost of providing services in the alternative setting is no more expensive than services in an institution.

Thirty-five States have waivers for programs—for persons with developmentally disabilities. There are 24 statewide programs and another 22 waiver programs that cover a portion of the developmentally disabled population in those states.

To participate in the Medicaid Program, an ICF/MR must meet Federal health, safety and active treatment standards. The State survey agency must survey the facility annually and certify its compliance.

With Congress help and urging, we have moved aggressively in the area of enforcement by looking behind the State surveys to assure that appropriate care is provided.

As Senator Weicker pointed out, the number of Federal surveyors has been increased, and we have added many specialists in developmental disabilities.

In addition to these Federal efforts, I might add that States have increased their own enforcement activities.

Let me just add one other quick point.

As you know, the committee——

Senator **Durenberger**. I should have cut you off. I mean, what is your quick one?

Mr. **Hackbarth**. We have recently published an NPRM which would result in a major overhaul of the regulations governing ICF/MR. We believe that is a very import effort, the effect of which would be to emphasize our activities on assuring an appropriate outcome of care as opposed to paper requirements. And at the appropriate time I would be glad to answer questions about that.

Senator **Durenberger**. All right.

Mr. **Hackbarth**. And with me is Carolyn Gray.

Senator **Durenberger**. Miss Gray, welcome.

[The prepared written statement of Mr. Hackbarth follows:]

DEPARTMENT OF HEALTH & HUMAN SERVICES

Washington, D.C. 20201

STATEMENT OF
GLENN HACKBARTH
DEPUTY ADMINISTRATOR
HEALTH CARE FINANCING ADMINISTRATION

BEFORE THE
SUBCOMMITTEE ON HEALTH
COMMITTEE ON FINANCE
UNITED STATES SENATE

SEPTEMBER 19, 1986

I am pleased to be here today to discuss the Health Care Financing Administration's commitment to services for the mentally retarded and other developmentally disabled persons. I will concentrate on the role which Medicaid plays in financing those services.

Introduction

During the 1960's there was a growing awareness of the generally poor care practices for persons with mental retardation living in institutions.

At that time, private organizations and State and local governments were primarily responsible for providing services to the mentally retarded and developmentally disabled. By the end of the decade the beginnings of essential reform activities were well underway which benefitted the mentally retarded and other developmentally disabled persons. As a result of litigation and increased societal recognition of the needs of this population, legislative initiatives in the 1970's created an array of additional entitlements and services.

Federally assisted programs are now the major source of financing for services for the retarded and developmentally disabled. Several amendments to the Social Security Act and specific entitlement programs for handicapped persons have created a diverse set of benefits for persons with developmental disabilities. These benefits include income support, medical services, educational and vocational services, and funds for rent subsidy, construction or renovation of specialized residential facilities. Medicaid is a program for low-income individuals who are disabled, aged, blind, under 21, pregnant or members of families with dependent children. Most mentally retarded and other developmentally disabled persons become eligible for Medicaid through a determination of disability under the Supplemental Security Income (SSI) program.

Once eligible, the full range of regularly provided Medicaid services in a State is available to any person, regardless of diagnosis, who is eligible and who receives the services in a Medicaid-covered setting. Services which States must provide include physician care, hospital care, outpatient hospital services, laboratory and x-ray services, and skilled nursing facility services. In addition, States may provide a broad array of additional health-related services, such as personal care, preventive care, case management, rehabilitative services and prescription drugs. Services specifically targetted for the retarded and persons with related conditions may also be included. For example, clinic services in many States are defined to include health-related services at community-based centers for the mentally retarded. And almost all States cover care in Intermediate Care

FACILITIES FOR THE RETARDED (ICFS/MR). IN ADDITION, STATES MAY PROVIDE, UNDER HOME AND COMMUNITY-BASED WAIVERS, SERVICES NOT NORMALLY COVERED BY MEDICAID, WHICH ARE TARGETTED TO PERSONS WITH DEVELOPMENTAL DISABILITIES. I WILL BRIEFLY DESCRIBE THESE SERVICES.

MEDICAID ICF/MR SERVICES

WHEN MEDICAID OPTIONAL COVERAGE OF ICFS/MR WAS ENACTED IN 1971, THE PURPOSE WAS TO PROVIDE EXPLICIT MEDICAID COVERAGE FOR THE MENTALLY RETARDED AND PERSONS WITH RELATED CONDITIONS LIVING IN INSTITUTIONS, BECAUSE OF A CONGRESSSIONAL CONVICTION THAT WITH "ACTIVE TREATMENT" THESE INDIVIDUALS MIGHT ACHIEVE A MAXIMUM LEVEL OF POTENTIAL FUNCTIONING. FORTY-EIGHT STATES AND THE DISTRICT OF COLUMBIA CURRENTLY COVER ICFS/MR UNDER THE MEDICAID PROGRAM.

ICF/MR SERVICES ARE COVERED WHEN AN ELIGIBLE RECIPIENT REQUIRES AND RECEIVES ACTIVE TREATMENT IN A FACILITY WHICH MEETS ALL THE STANDARDS PRESCRIBED IN THE LAW AND REGULATIONS. THE REQUIREMENT THAT THE CLIENT NEED AND RECEIVE ACTIVE TREATMENT WAS INSERTED IN THE AUTHORIZING LEGISLATION IN ORDER TO AVOID THE CONTINUATION OF A LONG HISTORY OF CUSTODIAL CARE FOR RETARDED PERSONS. ACTIVE TREATMENT REQUIRES THAT CLIENTS RECEIVE CARE AND SERVICES TO HELP THEM FUNCTION AT THEIR HIGHEST POSSIBLE LEVEL.

WHEN THE ICF/MR BENEFIT WAS FIRST INSTITUTED, MOST PARTICIPATING FACILITIES WERE LARGE PUBLIC INSTITUTIONS. HOWEVER, OVER THE LAST DECADE AN INCREASING NUMBER OF SMALL COMMUNITY-BASED FACILITIES HAVE BECOME ICF/MR PROVIDERS. AS OF MAY, 1986 THERE WERE 3251 CERTIFIED ICFS/MR WITH 149,000 BEDS. THEY MAY BE DESCRIBED AS FOLLOWS:

- 2400 (75%) OF THESE FACILITIES HAVE 15 OR FEWER BEDS,
- 730 (22%) HAVE 16 TO 300 BEDS, AND
- 121 (3%) ARE PREDOMINANTLY LARGE INSTITUTIONS WITH MORE THAN 300 BEDS.

TWENTY-FIVE PERCENT OF THE ICFS/MR ARE PUBLIC FACILITIES. THESE SERVE APPROXIMATELY 100,000 CLIENTS, AND ARE GENERALLY LARGER FACILITIES. SEVENTY-FIVE PERCENT ARE PRIVATE FACILITIES. THEY SERVE APPROXIMATELY 46,000 CLIENTS, AND ARE GENERALLY SMALLER FACILITIES.

AS OF 1982, 80 PERCENT OF THE CLIENTS LIVING IN PUBLIC FACILITIES WERE FUNCTIONING WITHIN THE SEVERE AND PROFOUND RANGE OF MENTAL RETARDATION, WHILE 66 PERCENT OF THE CLIENTS IN SMALL FACILITIES WERE FUNCTIONING IN THE MILD TO MODERATE RANGE OF RETARDATION. LARGE PUBLIC FACILITIES FOR THE MENTALLY RETARDED ARE NOW SERVING THE MOST SEVERELY DISABLED PERSONS IN OUR SOCIETY WHILE SMALLER, PRIVATELY OPERATED, COMMUNITY-BASED FACILITIES TEND TO SERVE LESS DISABLED PERSONS.

A belief that persons with developmental disabilities should be served in the least restrictive setting and concerns about increasing costs of long-term institutional care led to a general perception that many individuals could be provided care more appropriately and cost-effectively in smaller facilities (group homes) or in other home and community-based settings.

Both Congress and HCFA have been working to test this hypothesis: Congress, through a series of waivers to encourage home and community-based care; and HCFA through reforms in the ICF/MR standards that make it easier for smaller facilities in the community to meet Medicaid's health and safety requirements.

Medicaid Home and Community-Based Waiver Services

This desire to provide more individually responsive, yet lower cost alternatives to institutional care is reflected in Section 2176 of the Omnibus Budget Reconcilitiation Act of 1981 (P.L. 97-35), which authorizes the Secretary to waive certain Medicaid requirements to enable States to provide a variety of home and community-based services to recipients who otherwise would need Medicaid covered SNF or ICF (including ICF/MR) care. In order to obtain a waiver, a State must demonstrate that the cost of providing services in the alternative setting is no more expensive than providing the services in an institutional setting. A State may provide case management, homemaker, home health aide, personal care, habilitation, and respite care services as well as other services established by the State and approved by HCFA. The statute specifically precludes payment for room and board from coverage under a waiver.

Thirty-five States have waivers for programs for persons with developmental disabilities. There are 24 State-wide programs and another 22 waiver programs that cover a portion of the developmentally disabled population in those States.

In summary, Medicaid is serving 146,000 persons in ICFs/MR, at a cost of $4.7 billion in 1985, and 21,000 persons in home and community-based programs at a cost of $161 million. In addition, Medicaid is serving many retarded and developmentally disabled persons who are not in ICFs/MR or receiving services under home and community-based waivers, but who have limited income and meet the SSI definition of disabled.

Health and Safety Concerns

As I mentioned earlier, the ICF/MR benefit was established to promote the growth of and to protect persons with developmental disabilities living in institutions. We continue to remain concerned about the care provided to clients in ICFs/MR. In order

TO PARTICIPATE IN THE MEDICAID PROGRAM AN ICF/MR MUST MEET FEDERAL HEALTH, SAFETY, AND PROGRAM (ACTIVE TREATMENT) STANDARDS. THE STATE SURVEY AGENCY MUST SURVEY THE FACILITY ANNUALLY AND CERTIFY ITS COMPLIANCE WITH THE REQUIREMENTS.

IN RECENT YEARS, WE HAVE REALIZED THAT WE NEEDED TO MOVE AFFIRMATIVELY IN TWO AREAS. THE FIRST IS ENFORCEMENT OF STANDARDS. TO ASSURE THAT FACILITIES LIVE UP TO OUR REQUIREMENTS, WE HAVE BEGUN TO "LOOK BEHIND" WHAT THE STATES HAVE DONE WHEN THEY SURVEY A FACILITY. THE SECOND AREA IS IN FACILITY STANDARDS. WE HAVE SEEN THE NEED TO WRITE NEW STANDARDS THAT (1) RECOGNIZE THE IMPORTANCE OF CLIENT CARE OUTCOMES, AND (2) PROVIDE THE FLEXIBILITY NECESSARY TO PERMIT SMALLER, COMMUNITY FACILITIES TO PARTICIPATE AS ICFS/MR.

WITH CONGRESS' HELP, WE HAVE MOVED QUICKLY IN THE AREA OF ENFORCEMENT. THE NUMBER OF FEDERAL SURVEYORS, MANY OF WHOM ARE SPECIALISTS IN DEVELOPMENTAL DISABILITIES, HAS BEEN INCREASED OVER THE PAST 2 YEARS, AND WE HAVE INCREASED THE NUMBER OF FEDERAL LOOK BEHIND SURVEYS. IN 1985 WE CONDUCTED 464 FEDERAL ICF/MR SURVEYS. IN SEVENTY-TWO CASES FACILITIES WERE NOTIFIED THAT CHANGES WERE NEEDED IN ORDER FOR THE FACILITY TO CONTINUE TO PARTICIPATE IN THE PROGRAM. IN FORTY-ONE OF THOSE CASES DEFICENCIES WERE FOUND THAT POSED A SERIOUS AND IMMEDIATE THREAT TO THE CLIENTS' HEALTH AND SAFETY. THE MOST FREQUENT SERIOUS DEFICIENCY INVOLVED THE FINDING THAT CLIENTS WHO NEEDED ASSISTANCE WERE LIVING IN BUILDINGS THAT WERE NOT FIRE RESISTANT. THIRTY-NINE OF THE 41 FACILITIES MADE IMMEDIATE CORRECTIONS AND THUS CONTINUED AS MEDICAID PROVIDERS. THE MAJOR DEFICIENCIES IN THE OTHER 31 FACILITIES INCLUDED FAILURE TO ADEQUATELY PROVIDE ACTIVE TREATMENT SERVCES, INSUFFICIENT DIRECT CARE AND PROFESSIONAL STAFF, AND PHYSICAL ENVIRONMENT PROBLEMS. TWENTY-FIVE OF THESE FACILITIES CORRECTED THE DEFICIENCIES IMMEDIATELY OR SUBMITTED ACCEPTABLE PLANS OF CORRECTION. THOSE FACILITIES WHICH FAILED TO ADEQUATELY ADDRESS THEIR DEFICIENCIES WERE TERMINATED.

THIS YEAR WE HAVE CONDUCTED 514 SURVEYS AND 80 FACILITIES HAVE BEEN NOTIFIED OF PENDING ADVERSE ACTIONS. THROUH THIS EFFORT WE HAVE LEARNED TO IDENTIFY PROBLEM FACILITIES AND WILL SOON INITIATE A REVISED METHODOLOGY FOR FOCUSING ON THESE FACILITIES. THERE IS NO DIMINUTION OF OUR COMMITMENT TO ENSURING AGRESSIVE, ACCOUNTABLE MONITORING OF THE ICF/MR PROGRAM AT THE FEDRAL LEVEL.

IN ADDITION TO THESE FEDERAL EFFORTS, STATES HAVE INCREASED THEIR ENFORCEMENT ACTIVITIES IN 1985. STATES HAVE ON THEIR OWN INITIATIVE, DECERTIFIED 25 ICFS/MR AND 31 HAVE VOLUNTARILY WITHDRAWN FROM THE PROGRAM. A NUMBER OF OTHER ADVERSE ACTIONS ARE PENDING.

IN PURSUIT OF OUR SECOND OBJECTIVE, TO MODIFY ICF/MR STANDARDS TO KEEP PACE WITH CHANGES IN TREATMENT SETTINGS AND PRACTICES, WE ARE REVISING FEDERAL REQUIREMENTS. THE CURRENT STANDARDS WERE PUBLISHED

IN 1974, AND WERE BASED ON THE STATE OF THE ART AT THAT TIME. SINCE 1974, LITIGATION, LEGISLATION, RESEARCH AND TECHNOLOGICAL ADVANCES HAVE INFLUENCED THE WAY IN WHICH CLIENTS ARE IDENTIFIED, ASSESSED AND PROVIDED SERVICES.

IN THE PROPOSED STANDARDS, WE HAVE DRAWN FROM THE ACCREDITATION STANDARDS PUBLISHED IN 1983 BY THE ACCREDITATION COUNCIL FOR SERVICES TO MENTALLY RETARDED AND OTHER DEVELOPMENTALLY DISABLED PERSONS(ACMRDD), AND FROM SUBSTANTIAL DISCUSSION WITH A BROAD RANGE OF ORGANIZATIONS AND INDIVIDUALS KNOWLEDGEABLE IN THE FIELD. THE PROPOSED STANDARDS CLEARLY DEFINE AND BRING TOGETHER THE ACTIVE TREATMENT REQUIREMENTS. THEY ARE DESIGNED TO BETTER ENABLE BOTH THE FACILITY AND MONITORING AGENCIES TO FORM JUDGMENTS ABOUT WHETHER INDIVIDUALS' NEEDS ARE BEING PROPERLY ASSESSED AND WHETHER APPROPRIATE INTERVENTIONS ARE BEING PLANNED AND DELIVERED. THE STANDARDS SHOULD PROVIDE GREATER FLEXIBILITY TO ALL OF THE VARIOUS SIZES OF FACILITIES IN THE ADMINISTRATION OF THEIR PROGRAMS. ALSO, THE STANDARDS SHOULD MAKE IT EASIER FOR HCFA AND THE STATES TO MEASURE THE OUTCOMES OF CARE.

WE RECEIVED SIGNIFICANT PUBLIC SUPPORT IN THE 235 COMMENTS ON THE PROPOSED REGULATION. WE ARE NOW REVIEWING THE COMMENTS AND DEVELOPING THE FINAL RULE.

I WOULD ALSO NOTE THAT IN APRIL OF THIS YEAR WE PUBLISHED FINAL REGULATIONS REVISING FIRE SAFETY REQUIREMENTS FOR ICFs/MR. AS A CONSEQUENCE, FACILITIES HAVE GREATER FLEXIBILITY IN MEETING THE STANDARDS BASED ON THE CLIENT'S ACTUAL ABILITY TO EXIT THE BUILDING IN THE EVENT OF A FIRE OR OTHER EMERGENCY.

INCREASING INCENTIVES FOR COMMUNITY LIVING

IN ORDER TO ADDRESS THE BROADER GOALS OF ENHANCING THE INDEPENDENCE, INTEGRATION AND PRODUCTIVITY OF MENTALLY RETARDED AND OTHER DEVELOPMENTALLY DISABLED PEOPLE, THE SECRETARY HAS ESTABLISHED AN INTRA-AGENCY WORKING GROUP TO DEVELOP COST-EFFECTIVE POLICY OPTIONS. THE WORKING GROUP WILL EXAMINE FEDERAL POLICIES AND PROGRAMS, INCLUDING MEDICAID ICFs/MR, AND CONSIDER POSSIBLE CHANGES THAT MAY INCREASE ACCESS TO COMMUNITY LIVING ARRANGEMENTS AND ENCOURAGE SELF-SUFFICIENCY. THE COMMITTEE IS EXPECTED TO HAVE RECOMMENDATIONS TO THE SECRETARY BY THE END OF MAY 1987.

WE ARE ALSO CONDUCTING A THOROUGH EVALUATION OF THE HOME AND COMMUNITY-BASED WAIVERS WHICH WILL ATTEMPT TO IDENTIFY THOSE PROGRAM, SERVICE, AND CLIENT-RELATED FACTORS WHICH ARE ASSOCIATED WITH COST-EFFECTIVENESS. SOME OF THE EVALUATION ISSUES WHICH WILL HELP GUIDE FUTURE POLICY DECISIONS INCLUDE:

- o SHOULD HOME AND COMMUNITY-BASED SERVICES CONTINUE TO BE SPECIFICALLY RELATED TO REDUCED RATES OF GROWTH IN THE NUMBER OF FACILITIES AND BEDS?
- o WHAT SERVICES ARE MOST EFFECTIVE IN MEETING THE NEEDS OF DEVELOPMENTALLY DISABLED PERSONS WHO ARE AT RISK OF BEING INSTITUTIONALIZED?
- o HOW ARE HOME AND COMMUNITY-BASED SERVICES BEST INTEGRATED WITH OTHER PROGRAMS?

WE EXPECT TO HAVE PRELIMINARY RESULTS OF THE EVALUATION EARLY NEXT YEAR.

THE HEALTH CARE FINANCING ADMINISTRATION IS COMMITTED TO ASSISTING IN MEETING THE NEEDS OF THE DEVELOPMENTALLY DISABLED IN THE MOST APPROPRIATE AND COST-EFFECTIVE SETTING. WE WILL WORK CLOSELY WITH OTHER FEDERAL AGENCIES AND DEPARTMENTS TO ACCOMPLISH THIS GOAL.

WITH ME HERE TODAY IS CAROLYN GRAY, ACTING DEPUTY ASSISTANT SECRETARY FOR THE OFFICE OF HUMAN DEVELOPMENT SERVICES (HDS). SHE WILL DISCUSS THE DEVELOPMENTALLY DISABLED POPULATION AND THE ACTIVITIES OF THE ADMINISTRATION ON DEVELOPMENTAL DISABILITIES. I THINK YOU WILL FIND THAT MANY OF THE ACTIVITIES OF HDS COMPLEMENT THOSE OF THE HEALTH CARE FINANCING ADMINISTRATION.

THAT CONCLUDES MY STATEMENT. I WILL BE GLAD TO ANSWER ANY QUESTIONS YOU MIGHT HAVE.

STATEMENT OF CAROLYN GRAY, ACTING DEPUTY ASSISTANT SECRETARY, OFFICE OF HUMAN DEVELOPMENTAL SERVICES, WASHINGTON, DC

Ms. GRAY. Thank you, Mr. Chairman, for the opportunity to testify today concerning the characteristics of persons with developmental disabilities and the programs the Office of Human Development Services [HDS] administers in support of a continuum of services for this vulnerable population.

Developmental disabilities are defined in the Developmental Disabilities Act of 1984 as severe, chronic disabilities attributed to mental or physical impairments manifested before age 22, which substantially limit at least three areas of major life activity and result in the need for services over an extended period of time.

We estimate that there are approximately 3.9 million persons with developmental disabilities in the United States, approximately 2 million of whom are over the age of 18.

Persons served in institutions represent only a small percentage of this population. About 146,000 persons reside in intermediate care facilities for the mentally retarded.

Within HDS, the mandate of the Administration for Developmental Disabilities—ADD—is to assist States to assure that persons with developmental disabilities receive necessary services, and that their legal and human rights are protected.

This mandate is implemented through ADD's administration of, one, Basic State Grants which help States to plan, coordinate, and administer services for persons with developmental disabilities; two, protection and advocacy grants, which are awarded to State agencies to pursue legal, administrative, and other appropriate remedies to insure the protection of rights of developmentally disabled individuals; three, special projects, which are made to a variety of public and private organizations for projects of national significance; and four, a national network of 36 university affiliated facilities and 7 satellite centers. These elements of the ADD program complement State service delivery systems.

At the national level, ADD coordinates with the various agencies that provide funding for services needed by this population, including the Health Care Financing Administration, the Social Security Administration, the Department of Education, and the Department of Housing and Urban Development.

ADD cochairs the Interagency Committee on Developmental Disabilities, which is mandated by Public Law 98-527 to coordinate and plan relevant Federal activities.

In addition, ADD participates in the newly formed Secretary's Work Group on Policies Affecting Services for Mentally Retarded and Other Developmentally Disabled People. The work group is charged by the Secretary to examine Federal policies and programs, including Medicaid-funded intermediate care facilities, and to recommend changes that will increase access to community living arrangements and encourage self-sufficiency.

ADD provides leadership for the employment initiative campaign. Since the campaign's inception, 87,000 developmentally disabled workers have been employed in private sector jobs. The employment initiative has shown that, given proper support services, persons with developmental disabilities can lead more productive and self-sufficient lives.

In conclusion, we are committed to promoting the full participation in society by persons with developmental disabilities. The early success of the employment initiative shows that, with appropriate support services, most persons with developmental disabilities can lead lives that are more productive, independent, and self-sufficient.

We look forward to the day when all persons participate. in society to the fullest extent of their ability, and to a time when hireability is not limited by disability.

Thank you.

[The prepared written statement of Ms. Gray follows:]

STATEMENT OF

CAROLYN D. GRAY

ACTING DEPUTY ASSISTANT SECRETARY

FOR HUMAN DEVELOPMENT SERVICES

BEFORE THE

SUBCOMMITTEE ON HEALTH

COMMITTEE ON FINANCE

UNITED STATES SENATE

SEPTEMBER 19, 1986

Mr. Chairman, thank you for the opportunity to testify today before the Health Subcommittee of the Senate Finance Committee.

As Mr. Hackbarth mentioned, the activities of the Administration on Developmental Disabilities in the Office of Human Development Services do indeed complement those of the Health Care Financing Administration. Consequently, my remarks will discuss the characteristics of persons with developmental disabilities and the programs we administer that support a continuum of services for this vulnerable population.

The Developmentally Disabled Population

Developmental disabilities are defined in the Developmental Disabilities Act of 1984 as severe, chronic disabilities attributed to mental or physical impairments manifested before age twenty-two. These impairments cause substantial limitation in at least three areas of major life activity and result in the need for services over an extended period of time. Limitations may be in the area of self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic independence.

We estimate that there are approximately 3.9 million persons with developmental disabilities in the United States. Of these, approximately two million are over the age of 18. Persons served in institutions represent only a small percentage of this population. About 146,000 reside in intermediate care facilities for the mentally retarded, or ICFs/MR.

Due to their functional limitations, persons with developmental disabilities commonly need some level of service on a long-term basis. Such services may include:

- Supported living arrangements
- Educational and vocational training
- Supervised social activities
- Speech therapy
- Physical therapy
- Case management, and
- A variety of other services.

Many persons with developmental disabilities have multiple handicaps and may require extensive training and assistance to accomplish even the most routine tasks. Accordingly, they are among the most vulnerable and difficult population to serve.

Overall Purpose of the Developmental Disabilities Program

The Administration for Developmental Disabilities (ADD) seeks to integrate these persons into the existing network of public and private sector providers. Specifically, ADD is charged to

- assist States to assure that persons with developmental disabilities receive the services necessary to enable them to achieve their maximum potential through increased independence, productivity, and integration into the community; and,
- assist States to establish and operate a system which protects the legal and human rights of persons with developmental disabilities.

Structure of the Developmental Disabilities Program

The ADD program has several components:

1) Basic State Grants;

2) Protection and Advocacy Grants

3) Special Projects, and

4) University Affiliated Facility Grants

Basic State Grants:

Basic State Grants help States to plan, coordinate, and administer services for persons with developmental disabilities.

Funds are awarded to each State by formula to support the activities of a State Developmental Disabilities Planning Council. The Councils are comprised of representatives of major State and Federal programs, service providers, and developmentally disabled persons and their families. As part of a three-year improvement plan, each Council selects one or two of the following priority service areas as a focus of activity:

- Case Management;
- Child Development Services;
- Alternative Community Living Arrangements; or
- Employment-related Activities.

Protection and Advocacy:

Protection and Advocacy grants are awarded by formula to State Protection and Advocacy agencies, which must be independent from any entity which provides services to persons with developmental disablilities. These agencies must have the authority to pursue legal, administrative, and other appropriate remedies to insure the protection of the rights of developmentally disabled individuals who are receiving treatment, services, or rehabilitation within the State.

Special Projects:

Through mechanisms such as the Office of Human Development Services' Coordinated Discretionary Program, grants are made to a variety of public and private organizations for projects of national significance.

University Affiliated Facilities:

Grants support a national network of 36 University Affiliated Facilities and 7 Satellite Centers. These facilities provide interdisciplinary training, technical assistance, and information dissemination, and demonstrate exemplary service models.

Approximately 57,000 individuals with developmental disabilities and their families receive direct services each year from the Unversity Affiliated Facilities and Satellite Centers.

The Role of the DD Program Within the Service Delivery System

These elements of the ADD program complement State service delivery systems. State Councils monitor the service delivery network. Protection and Advocacy agencies ensure that the legal and civil rights of persons with developmental disabilities are protected. University Affiliated Facilities provide academic and professional training and ensure that there is a professional and paraprofessional workforce prepared to meet the service needs of this population. Discretionary funds help demonstrate improved methods and services.

National Coordination Efforts

At the national level, ADD coordinates with the various agencies that provide funding for services needed by this population. These agencies include the Health Care Financing Administration, the Social Security Administration, the Department of Education, and the Department of Housing and Urban Development. ADD co-chairs the Interagency Committee on Developmental Disabilities, which is mandated by P.L. 98-257 to coordinate and plan relevant federal activities. In addition, ADD participates actively in the newly formed Secretary's Work Group on Policies Affecting Mentally Retarded and Other Developmentally Disabled People. I will discuss the Work Group shortly. Finally, ADD has engaged the private sector in promoting self-sufficiency for persons with developmental disabilities through the Employment Initiative Campaign.

Secretary's Departmental Work Group

Recognizing the goal of self-sufficiency and the obstacles that may prevent it from being realized, Secretary Bowen has created an Interdepartmental Work Group on Policies Affecting Mentally Retarded and Other Developmentally Disabled People. The Work Group is a follow-up to the Report to Congress on Policies for Improving Services to Mentally Retarded and Other Developmentally Disabled Persons Under Title XIX of the Social Security Act. The Work Group is charged by the Secretary to examine Federal policies and programs, including Medicaid-funded intermediate care facilities, and to recommend changes that will increase access to community living arrangements and encourage self-sufficiency. The Group will forward its recommendations to the Secretary in early 1987.

Employment Initative Campaign:

President Reagan announced the Employment Initiative Campaign in November of 1983 as part of the National Decade of Disabled Persons. The campaign demonstrates that Americans with developmental disabilities can be a viable segment of the work force. The results to date have been most rewarding.

In the first two years since the campaign's inception, 87,000 workers who have developmental disabilities have been employed in private sector jobs. They will earn about $400 million in gross annual taxable wages, while the combined savings in public support costs and services will total nearly another $400 million.

This extraordinary accomplishment is due to the active support of corporations such as Radisson Hotels, Denny's Restaurants, and McDonalds Corporation, and trade associations, including the American Hospital Association, and the National Restaurant Association, among others.

The Employment Initiative has shown that, given proper support services, persons with developmental disabilities can lead more productive and self-sufficient lives.

Conclusion

In conclusion, we are committed to promoting the full participation in society by persons with developmental disabilities. That goal is not simply a humanitarian vision, it is in the best interest of persons with developmental disabilities, their families and communities and, thus in the best interests of all taxpayers.

The early success of the Employment Initiative shows that, with appropriate support services, most persons with developmental disabilities can lead lives that are more productive, independent and self-sufficient. We look forward to the day when all persons participate in society to the fullest extent of their ability, and to a time when hire-ability is not limited by dis-ability.

Thank you, Mr. Chairman, for the opportunity to testify on behalf of the Office of Human Development Services. I would be happy to answer any questions.

Senator **Durenberger**. Thank you very much. I thank you both.

Let me ask a couple of questions. Later, witnesses will say that—and it has been alluded to already by my colleagues—that the Medicaid Program is biased in favor of institutional care to the exclusion, perhaps, of community care; that Medicaid funding is tied to the number of certified beds and not to the specific needs of different people; and that the meaningful statistic to look at is not the percentage of institutions over a certain bed size, which might appear relatively small, but the percentage of the developmentally disabled population that is served in those institutions.

Can you tell us anything more specific about HCFA, either responds, or would respond to those statements?

Mr. **Hackbarth**. Yes.

It is in fact true that the vast bulk of the recipients are still in the largest institutions. But I think we have been making substantial progress in recent years. We have taken a number of steps that we think have facilitated the movement away from the largest institutions to smaller facilities. For example, back in 1981, we took some steps to clarify how the existing regulations could be applied to smaller facilities, and through that process tried to make the requirements more flexible and make them accommodate the special needs of small facilities better.

Of course, one of the primary purposes of the proposed rules that we published this spring was to do the same thing. The regulations, when first published in 1974, had an orientation that was very much directed at the large institutions which predominated at that time. One of the reasons for the overhaul of the regulations is to assure that they accommodate the change that has been occurring in the delivery system.

Through that regulatory process, as I said earlier, we hope to come up with a system that emphasizes not rigid institutional requirements—paper compliance and the like—but the outcome of the services provided to this population. And we think through that process we will aid the participation of the smaller facilities.

Senator **Durenberger**. Speaking of proposed rules, at the end of July—I think it was July 25—of this year, HCFA published a rule which would provide State Medicaid agencies with options when an ICF/MR is found to have deficiencies that "do not pose an immediate threat to the client's health and safety", either to correct the necessary staff and physical plant deficiencies within 6 months of the approval date of the plan or to reduce permanently the number of beds and certified units within 36 months of the approval date of the plan.

My mail tells me that there is concern out there that this rule might be used to prematurely close facilities without regard to what services are available in the community, or covered by the State's Medicaid Program.

What comments has HCFA received on the regulation? Do you have plans with regard to the final regulation?

Mr. **Hackbarth**. Yes.

It is certainly not our goal to force the delivery system to fit a certain mold. The way we view our role is to accommodate changes that are occurring in the delivery system and changes that the States would like to make.

After all, the Medicaid Program is a program that is primarily managed by the States at the State level. Thus, we believe it would be inappropriate to take regulatory or financing steps that would dictate that the State delivery system take on a certain shape. So we would not have the intent of prematurely closing large facilities when there aren't other facilities available to take up the slack.

As far as our plans for the regulation, we are in the process of reviewing the comments and hope to have the final regulation published late this fall.

Senator DURENBERGER. All right.

John Chafee?

Senator CHAFEE. Thank you very much, Mr. Chairman.

I would like to pursue two points, the first on the subject of what you are doing to encourage the community living facility.

As I understand it, Secretary Bowen submitted a report this year on the utilization of Medicaid funds, and he established four Departmentwide goals. I won't go into each of those, except the last one, "To increase incentives for community living."

So I understand from your remarks that, yes, you do support community living in certain instances, and so forth, but are you increasing the incentives for it?

Mr. HACKBARTH. Uh huh.

Senator CHAFEE. I mean, I start with a presumption, because I have seen it in my own State and elsewhere, and we have had, as we are listening here, a lot of testimony that the community living facilities and the community living for the individual is the best way to go. Now you can argue whether it is for 100 percent of the people. Let's not say for everybody. I personally believe everybody, but never mind.

Mr. HACKBARTH. Uh huh.

Senator CHAFEE. For the great fall.

Now what are you doing to increase these incentives?

Mr. HACKBARTH. Well, of course, the home and community based care waiver program I think does in fact establish both appropriate incentives and flexibilities for the States to move in that direction if they so desire.

Senator CHAFEE. Now could I just pursue that subject briefly?

Mr. HACKBARTH. Sure.

Senator CHAFEE. To waive a program they have got to get, they have got to apply for and there's a string on it. Last year, we increased the waiver. Review of the waiver is now 5 years. They never know whether they are going to get it again. It is fringed with restrictions, and so forth.

For example, yes, in your testimony you indicated that I think, 35 States have waivers now. But do you have figures on how many patients—clients, if you would, individuals—are covered by those waivers?

Mr. HACKBARTH. Yes, I do have that figure. There are 61,000.

Senator CHAFEE. As opposed to how many in the institutions?

Mr. HACKBARTH. Roughly, 146,000.

Senator CHAFEE. All right.

Now lets go back to, in other words, my view is that this waiver business keeps everybody on edge and is a handicap, or a hurdle, that I don't think the States should be made to leap through all the time. What are your views on that? Well, get rid of the waiver. Say that, yes, if you have a plan for community living arrangements, and your plan includes proper preparation, proper licensing of the facilities, that there's an appeal process by the parent or the individual guardian in the event that the person is being moved from an institution. Why don't we just have that in law instead of having this waiver harassment, if you would? I believe that is too strong a term.

Mr. **Hackbarth**. Of course, we don't view it as harassment. As you well know, there are certain requirements set out in the statute for the waivers, and what we are trying to do is implement the will of Congress, for example, to assure that the services are provided to people who would have been institutionalized or at risk of institutionalization, and that the aggregate costs are no more than would have been incurred had they been institutionalized. Those are requirements that we have to meet.

I can sympathize and understand the States' frustration sometimes in our efforts to meet those requirements, but those are things we have to do. They are not at our option.

Senator **Chafee**. Well I am asking you whether you think they should remain in the law?

Mr. **Hackbarth**. Well, in principle, I think that those are reasonable requirements; yes, sir.

Senator **Chafee**. Now, Senator Durenberger touched on this, and I wasn't sure that I understood the answer. Last year in the reconciliation bill we had a provision dealing with allowing States to phase down the population of one of these ICF/MR facilities without having it totally—the facility—totally being physically renovated as long as the lifesaving measures were taken.

Now, it is my understanding that this provision has not been made available to Colorado and Hawaii, who both applied, because the final regulations have not been published. Yet, when we passed that—and I was the sponsor of that amendment, as perhaps you will remember—the language in the bill clearly states that this provision was effective upon enactment and not dependent upon the issuance of regulations. What is your answer to that?

Mr. **Hackbarth**. As I recall, there was some language—perhaps in the committee report; I can't remember for sure—that it in fact did refer to the need of published regulations. And, of course, that is something that we would do as a matter of course, since to implement this particular provision does require some judgments to be made. And in fairness to everybody, we have to have those judgments made according to set criteria, so that they are available to everybody to know what the rules of the game are, so to speak.

So, in principle, the provision I think is one that is appropriate for regulation, to implement with regulations.

As far as the specific needs of Hawaii and Colorado are concerned, our problem is an administrative one. If we were to make the provision, in essence, retroactive, we would have to open up decisions that have already been made or further complicate negotiations that are already in process to resolve specific identified problems. And so to do anything on a retroactive basis is very complicated from an administrative standpoint. And that is why we would prefer to have a provision that is prospectively effective.

Senator **Chafee**. Well, you know the thrust of the legislation.

Mr. **Hackbarth**. Yes, sir.

Senator **Chafee**. And it was to not require States to pour money into renovation of a facility that they are planning to close. And we all acknowledge that safety measures in any lifesaving type of steps had to be taken. But if it is question of putting on a new roof when the old roof can get us through, get them through, a year or so, don't bother.

Now, yet, I am not sure of the details in either Hawaii or Colorado, but it is my understanding that they have been frustrated in their attempts to comply with the statute that we passed last year.

Mr. **Hackbarth**. Uh huh.

Senator **Chafee**. Are you familiar with those?

Mr. **Hackbarth**. I am not familiar with the details of either of those cases.

Senator **Chafee**. Well, it was effective upon enactment. And I just hope that you folks would get going on those regulations. The way your attorneys tell you you cannot proceed without the regulations. Everybody always say yes, but——

Mr. **Hackbarth**. Again, Senator, I think—I am an attorney by training—and I think as a matter of principle it is appropriate to have a broad provision like that implemented through regulations. If we did not do that, we would be criticized or open to potential criticism for arbitrary decisions that were not made according to clear standards, et cetera. And so we have to protect ourselves, so to speak, on both sides. And I do think that is a reasonable judgment on our part.

Senator **Chafee**. All right. I don't want to debate this ad nauseam here, but we can discuss this later on. Thank you.

Senator **Durenberger**. John Heinz.

Senator **Heinz**. Mr. Chairman, thank you very much.

I just want to ask the witness from the administration to clarify one thing. We are talking about the Medicaid Program, and the Medicaid Program is a very strictly means tested program, is it not?

Mr. **Hackbarth**. Yes, it is.

Senator **Heinz**. It serves very poor people, does it not?

Mr. **Hackbarth**. Yes.

Senator **Heinz**. Now, the second issue is, how we can facilitate when it is medically appropriate the de-institutionalization of Medicaid poor beneficiaries for whom Medicaid is paying full room and board and health care for in an institution, how we can facilitate their transition and maintenance in independent living? So far, that is correct, is it not?

Mr. **Hackbarth**. Uh huh.

Senator **Heinz**. Do we not pay as the Federal Government pretty close to half the cost of institutionalization of Medicaid patients? Isn't it at least that amount in some States and more in others?

Mr. **Hackbarth**. You are saying that roughly half of Medicaid expenditures go for institutional care.

Senator **Heinz**. For the Federal Government cost, roughly.

Mr. **Hackbarth**. That's in the ballpark, yes.

Senator **Heinz**. I mean, it varies by State——

Mr. **Hackbarth**. Yes, it does.

Senator **Heinz** [continuing]. From maybe as low as 45 percent to maybe as high as 55 or 58 percent, if I recollect it.

Mr. **Hackbarth**. Uh, huh.

Senator **Heinz**. But it is about half.

Now, were these what I will call medically necessary services to facilitate independent living, available? Would the Federal Government pay all, none, or approximately half of those costs?

Mr. **Hackbarth**. Well, I suppose——

Senator **Heinz**. When you grant a waiver—have you granted any waivers?

Mr. **Hackbarth**. Yes, we have.

Senator **Heinz**. When those waivers are granted, who bears the cost? How is that divided between State, local, non-Federal sources and the Federal Government?

Mr. **Hackbarth**. The same way as under the rest of the program.

Senator **Heinz**. The same way?

Mr. **Hackbarth**. Yes, sir.

Senator **Heinz**. My question, I guess, is, since we are paying half the cost of institutionalization, and institutionalization is inherently expensive.

Mr. **Hackbarth**. Uh, Huh.

Senator **Heinz**. And to the extent—by the way, we don't pay our full and fair share of that; the cost is just shifted onto some non-Medicaid institutionalized person, a private pay person, for example—so there is no real saving to the taxpayer there. They get stuck no matter what happens.

My question is this: If we have the same share, if the States have the same share, wouldn't it be irrational for States to adopt regulations that were not cost effective? If you are afraid of the Federal Government losing money on the provision of services to facilitate deinstitutionalization, aren't the States in exactly the same boat?

Mr. **Hackbarth**. I am not sure if I get the thrust of your question, but are you asking——

Senator **Heinz**. Well, the cost is shared between the Federal Government and the State government—the States that are asking you to grant waivers.

Mr. **Hackbarth**. Uh huh.

Senator **Heinz**. You, I presume, are concerned about the cost. At least I thought I heard you say earlier. And I am saying the incentives to minimize costs are just as great to the States as they are for you.

Mr. **Hackbarth**. So is your question, would we agree to eliminating from the requirements——

Senator **Heinz**. Well, my first question is, Do you agree that the incentives are the same?

Mr. **Hackbarth**. No, sir, I would not.

Senator **Heinz**. Why is that?

Mr. **Hackbarth**. Because often the Federal Government pays the majority of the costs. The matching rate exceeds 50 percent. So we have a higher interest, if you will——

Senator **Heinz**. But we just established that it is approximately 50 percent. If you are saying yes, sometimes the Federal Government pays 52 or 53 percent, and the States pay 47 or 48 percent, I just don't think that is a material difference.

Mr. HACKBARTH. No. I think we are talking about different things. And I thought your original question was, what percentage of Medicaid dollars go to institutional care? That number, I think, is around 50 percent. But, in fact, the Federal matching rate often substantially exceeds 50 percent. So, yes, the Federal Government does have——

Senator HEINZ. What does the matching rate for these services average?

Mr. HACKBARTH. For institutional services, in particular? It would be the same as anything else.

Senator HEINZ. So both the matching rate for services and for institutions is about the same, isn't it?

Mr. HACKBARTH. Our matching rate is constant across the full range of Medicaid services, yes.

Senator HEINZ. Well, if the chairman will allow me just to proceed 30 seconds more. I am puzzled by what you have just said, because if the matching rate is the same for both services and institutionalization to the Federal Government, and if it is somewhere around 50 percent—it might be 55 percent Federal, maybe it is——

Mr. HACKBARTH. Often it is substantially higher than 55 percent.

Senator HEINZ. Well how much higher?

Mr. HACKBARTH. Up to 78 percent Federal.

Senator HEINZ. And what is the average? What is the national average?

Mr. HACKBARTH. I suppose it would depend on how you weight the average.

Senator HEINZ. Well you don't need to weight the average. I am asking for the arithmetic mean.

Mr. HACKBARTH. The average is above 50 percent.

Senator HEINZ. Not a mode, not a median. I am asking for an arithmetic mean; take the dollars on both sides then add them up, and make a percentage.

Mr. HACKBARTH. The average rate is above 50 percent.

Senator HEINZ. About 50 percent.

Mr. HACKBARTH. Above 50 percent.

Senator HEINZ. Above. But you are telling me that it is as high as 70-some percent.

Mr. HACKBARTH. Yes.

Senator HEINZ. Then you have great precision when you tell me how high it may go. When I asked you what the average is, you are saying, oh, well, that is just something above 50 percent. I don't know. Now I don't think you can have it both ways.

Mr. HACKBARTH. I can give you that number.

Senator HEINZ. If you have got information that tells you that it goes up to 74 or 75 percent, you ought to have information as to what the average is.

Mr. HACKBARTH. Senator, I would be glad to supply that information for the record with great precision. I simply don't have it in my head.

Senator HEINZ. How many people are here from the Department?

Mr. DURENBERGER. Fifty-six percent. [Laughter.]

I think we could get it in writing. [Laughter.]

Mr. **Hackbarth**. Senator, I would still be happy to send the letter.

Senator **Heinz**. I would still like to know how many people are here from the Department. Would you all raise your hands?

[A showing of hands.]

Senator **Heinz**. Mr. Chairman, there are over a dozen people from the Department there.

Senator **Durenberger**. Fifty-six percent he said. [Laughter.]

Senator **Heinz**. Of the audience.

Senator **Durenberger**. You were here in 1978 and 1979. The whole room would be filled with Department people.

Senator **Heinz**. Well that is progress. [Laughter.]

Senator **Durenberger**. The chart bearers we used to call them.

Senator **Heinz**. Thank you very much.

Senator **Durenberger**. I take it we will follow up on Senator Heinz' line of questioning, is that all right, Glenn?

Mr. **Hackbarth**. Sure.

Senator **Chafee**. Mr. Hackbarth, one quick question. Some of the most poignant testimony we have received is from those parents—and frequently it is a single parent—who are, or is, taking care of a child—and in one instance it was two children—extremely disabled at home, and by doing that, are saving the Federal Government extraordinary sums of money, or all government, because those children could be in an institution. And the plea that comes across is, look, we are not asking that our child be in an institution. We don't want it. We are prepared to carry this ball ourselves to do what is necessary. But in the case, particularly of the single parent, the plea is for some respite care, a 2-week break.

We had a lady testify before and all she asked for was 2 weeks of relief. And when you could understand the schedule she had, I thought that was one of the most modest requests I had ever heard.

And yet under the waiver, it appears to be extremely difficult to get any Medicaid assistance for a situation like that. To me, it just doesn't make an awful lot of sense.

Could you briefly discuss what you know about that or have someone discuss it? First, the degree of difficulty of getting the waiver. And it is my understanding, a waiver that covers this. These waivers aren't across the board. Obviously, they are for a limited purpose. Could you discuss that briefly?

Mr. **Hackbarth**. Yes, sir.

As I understand it, you are correct, it is difficult. And this is one of the issues that the Secretary's work group is looking into.

Senator **Chafee**. Well I just want to put in a plea that it be granted. The savings—the claim, I am sure, will be, oh, well, these people that are attending their children at home will now suddenly flood forward and say we want some help. Well they ought to get the help, I think. And if you look at it the other way, if those parents suddenly said, we give up; you take care of these youngsters in the institutions, the cost to the Federal Government and the State governments would be astronomical.

And I was really touched by the testimony we had in those instances. So I hope you will proceed to provide that the waivers can cover respite care without an incredible number of hurdles for the State to go through.

Thank you, Mr. Chairman.

Senator **Durenberger**. John, thank you very much. Glenn and Carolyn, thank you very much.

We will now call up our next panel. Dr. Charlie Lakin, from the Center for Residential and Community Services, University of Minnesota. Charlie, if you would come up here first. I have got a young man who wants to take your picture. Then you can go back and testify. [Laughter.]

Senator **Durenberger**. Dr. David Braddock, from the University of Illinois at Chicago; James W. Conroy, director of research and program evaluation, Developmental Disabilities Center, Temple University; and Dr. David Mank, assistant professor, Division of Special Education and Rehabilitation, of the University of Oregon, in Eugene, OR.

I think all the witnesses are aware of the rules on the length of their testimony. Their statements are well done and will all be made part of the record of this hearing.

We will begin with Dr. Lakin.

STATEMENT OF K. CHARLIE LAKIN, PH.D., SENIOR SCIENTIST, CENTER FOR RESIDENTIAL AND COMMUNITY SERVICES, UNIVERSITY OF MINNESOTA, MINNEAPOLIS, MN

Dr. **Lakin**. Good morning. My name is Charlie Lakin. I am a researcher at the University of Minnesota.

Over the past 10 years, my colleagues and I have concentrated on gathering and maintaining national statistics on residential and related services for persons who are mentally retarded. Of obvious interest in that work has been the ICF/MR Program.

I believe the ICF/MR Program really has shown considerable success in attaining its original goals; notably, among those goals, were to improve the scandalous conditions existing in State institutions in and around 1970, and also to remove the incentives for States to place persons with mental retardation in nursing homes, or to certify their State institutions as skilled nursing facilities solely to obtain a Medicaid cost share.

While the success of this program is debatable, it is abundantly clear that the goals that it was established to meet are not the goals we should be striving for today.

In passing the Developmental Disabilities Assistance and Bill of Rights Act of 1984, Congress articulated well what we should be striving to obtain in policy and programs today. That act spoke of the intent, "to enable persons with developmental disabilities to achieve their maximum potential through increased independence, productivity, and integration." I hope Congress will weigh its actions and its inactions against that standard. If it does, I see little chance that the current ICF/MR Program will be judged as adequate.

I have come to the conclusion in my work that we need a significantly different Federal program to assist States in providing residential and related services. The ICF/MR Program may not prevent States from realizing the ideals, the DD Act, but it does nothing to encourage them. I think it is dramatically devoid of purpose when compared with programs such as the one Senator Chafee has proposed.

But whether Senator Chafee's bill or some other bill guides our Nation's commitment to mentally retarded persons, I believe an effective program must exhibit a number of qualities.

I believe it must stimulate States to actively pursue increased community integration of persons with mental retardation. There is no habilitative or cultural justification for a long-term commitment to segregated facilities.

It should ensure that appropriate standards exist for services and that effective and unbiased monitoring takes place.

It should be flexible and promote the availability of a wide variety of options for integrating the residential, productive and social lives of persons with mental retardation.

If the ICF/MR Program has taught us anything it is that there is no single one best model of care for all persons with mental retardation.

Our program should demonstrate much greater equity among States in the extent to which the Federal Government assists in support appropriate services. Today, States vary enormously in the proportion of their residential systems covered by Medicaid, and also in the amount contributed by the various Federal programs that are available to States to help support the costs of services.

I also believe our program should promote a much stronger relationship between the dollar amount the Federal Government contributes to the services for an individual and the level of impairment of that individual.

It may be that if we were to somehow alter the ICF/MR Program so that all people didn't receive the same level of care, this may happen automatically, but another means to encourage such a relationship would be to experiment with a limited number of impairment related groupings to determine a maximum level of Federal financial participation.

Almost exactly 10 years ago the General Accounting Office issued a report that found—

> Although the States are primarily responsible for the care and treatment of the mentally disabled, many problems are attributable to Federal programs which provide incentives that inhibit the appropriate placement of the mentally disabled, and the lack of leadership and actions by many Federal agencies whose programs do, could or should affect community placement.

It is going to be a terrible shame if that conclusion will remain valid for yet another decade.

Thank you.

Senator DURENBERGER. Thank you very much, Dr. Lakin. This is an interesting panel. We have got everybody spread out. We could get you all with one shot. [Laughter]

That was not a threat. Go ahead, Dr. Braddock.

[The prepared written statement of Dr. Lakin follows:]

Medicaid Services for Persons with Developmental Disabilities

(Testimony before the Subcommittee on Health,
Senate Committee on Finance, September 19, 1986)

My name is Charlie Lakin. I am Senior Scientist of the Center for Residential and Community Services, University of Minnesota. Because my invitation to testify obviously derives from my role as primary author of "An Analysis of Medicaid's Intermediate Care for the Mentally Retarded (ICF-MR) Program," I will generally restrict my observations to ones that derive directly from that report. The analysis of the ICF-MR program provided a two points in time look at changes in state operated, licensed, or contracted residential facilities for people with mental retardation, June 30, 1977 and June 30, 1982. Importantly, the study included both ICF-MR certified and noncertified facilities. The report also contains the results of two special surveys regarding the responses of states to the Medicaid waiver authority and state practices in reimbursing private ICF-MR care, as well as reviews of literature related to current policy issues (e.g., a legislative and regulatory history of the ICF-MR program, a survey of research on the different habilitative outcomes of placement in large and small residential facilities). Because the findings from this study are the most current and comprehensive statistics on ICF-MR certified and other residential facilities nationally, I would like to include some of these as part of my formal testimony. Where appropriate, these have been updated by more recent surveys of our Center.

Selected Findings Related to Medicaid Services

Regarding residential services generally

- *On June 30, 1982 state residential care systems (public and private, ICF-MR and non-certified facilities) had a total of 243,669 persons with mental retardation in 15,633 residential facilities.*

  - The 15,633 facilities nationwide had a total licensed bed capacity of 304,216 with a total residential population (retarded and non-retarded) of 279,095; they had an occupancy rate of 92%.

  - Average number of residents per facility was 15.6 nationwide; state averages varied from 8.8 persons per facility in Vermont to 122.4 per facility in Oklahoma.

- *States vary widely in their mental retardation placement rates* (i.e., the number of people with mental retardation in their state residential care systems per 100,000 of their general population). State placement rates varied in 1982 from 34 in Nevada to 184 in North Dakota, with the national average being 105.

* *The total number of people with mental retardation in state residential care systems has been stable since 1967, while the rate of placement has decreased significantly.*

-- In 1967, there were 254,000 residents with a primary diagnosis of mental retardation and mental health facilities (the latter then being used widely for residential placements of people who were mentally retarded); in 1982, there were 246,000.

-- In 1962 the national mental retardation placement rate (both mental retardation and mental health facilities) was 125 per 100,000 with states' rates varying from 40 (Nevada) to 232 (North Dakota); in 1982 the national rate was 106 with state rates varying from 34 (Nevada) to 184 (North Dakota).

-- Between 1967 and 1982 only 8 states increased their placement rates.

* *Average daily population of state institutions which peaked at 194,650 in FY 1967 has decreased every year since, falling to 105,000 in FY 1982.*

-- State institution populations have decreased at a steady rate of approximately 5,000 residents per year since Fiscal Year 1968.

-- The average daily population of state institutions in Fiscal Year 1985 (about 105,000) was only 54% of the Fiscal Year 1967 average.

-- The state institution placement rate (i.e., rate per 100,000 of the general population) fell from 99.0 to 47.8 nationally between 1967 and 1985.

-- State institution placement rates vary among the states from 15 in Alaska to 109 in North Dakota. (North Dakota has lowered its rate from 143 to 109 between FY 1978 and FY 1985.)

* *Today the number of people with mental retardation in private residential facilities surpasses the number in public residential facilities.*

-- In 1982 47.2% of residents were in private facilities.

-- Projecting the annual rate of change in residential placements by type of operation from 1977-1982, by June 30, 1985 an estimated 53% of people with mental retardation in state residential care systems were in private facilities.

-- In 1977 the privately operated proportion of state residential care systems ranged from a minimum of 4% in South Carolina to a maximum 67% in Maine; by 1982 the private share of state residential care systems had increased to 7% in South Carolina and to 73% in Maine.

- *In 1982 most persons with mental retardation in state residential care systems (84%) resided in group residences (i.e., facilities in which a paid staff provides care, supervision and training to residents).* This was almost the same percentage as in 1977 when 86% of residents were in such residential/training settings. However, there were notable changes in the sizes of the group residences between 1977 and 1982.

  -- Most group residence tenants (60%) are in large (16 or more residents) public facilities (122,971 of 205,330 in 1982). There was a significant total and proportional reduction from 1977 when 154,856 of 214,300 (72%) of group residence tenants were in large public facilities.

  -- Large private group residences (16 or more beds) had 40,347 total residents with mental retardation in 1982, up from 36,998 in 1977.

  -- Small group residences (15 or fewer residents) had 42,118 residents with mental retardation in 1982, an increase from 22,449 in 1977.

  -- The second most widely used model of care in state residential care systems in 1982 was specialized foster care (i.e., foster care homes with special licenses to serve people). In 1982 there were 17,147 such placements (an increase from 14,418 in 1977) with almost 10,000 of those in California and New York.

  -- One significance of the proportion of individuals in group residences (as defined above) is that such facilities are the most readily adaptable to certification as ICF-MR facilities (68.5% of residents of group residences in 1982 were ICF-MR certified facilities).

- *The average size of residential facilities has decreased rapidly.*

  -- The average number of residents per facility in state residential care systems in 1982 was 18.0, a decrease from 26.2 in 1977.

  -- In 1977 there were 9,294 small facilities (15 or fewer residents) nationwide with 40,433 mentally retarded residents; in 1982 there were 13,862 small facilities with 63,703 retarded residents.

Regarding ICF-MR facilities specifically

- *Between 1977 and 1982 the proportion of occupied residential system beds that were in ICF-MR certified facilities grew from 43% of the 247,800 total (certified and non-certified) to 58% of 243,700. An additional 7% growth in residents of ICF-MR facilities by June 1985 is estimated from a 1986 survey of 40 states.*

  -- The ICF-MR program had a net increase of 34,000 beds from 1977-1982, reaching a total of 140,684 on June 30, 1982. (The June 30, 1985 total is estimated to be about 150,000.)

  -- Most of the growth in ICF-MR beds between 1977 and 1982 was in facilities with more than 76 residents (a net increase of almost 20,000 beds out of a total net increase of 33,800 beds).

- In 40 states (with 85% of the 1982 ICF-MR population), between 1982 and 1985 there was a net growth of about 900 residents in ICF-MR facilities of more than 16 residents (about 8,000 more in large private ICF-MR facilities; about 7,000 fewer in large public facilities).

- The fastest growing segment of the program is the small ICF-MR facility. Small ICF-MR facilities (15 or fewer residents) had a net increase of almost 500% (7,000 residents) between June 30, 1977 and 1982. Between June 30, 1982 and 1985, 40 states witnessed a doubling from 8,400 to about 16,850 in small ICF-MR residents. (The 11 states which had not yet reported data for 1985 had a total increase of only 65 small ICF-MR facilities between 1982 and 1984--an estimated 350-400 residents.)

- Almost all growth in large (16 or more residents) facilities took place through certifying existing facilities for ICF-MR participation, while new small ICF-MR facility residents were generally placed in newly opened facilities.

• *The proportion of large public institution residents whose care was cost shared by the ICF-MR program substantially increased between 1977 and 1982.* In 1977 states had over 60,000 people with mental retardation in non-certified public institutions of 76 or more residents out of 152,500 residents altogether; by 1982 only 15,000 out of 120,000 total residents in public institutions were in non-certified beds.

• *A shift from public to private providers is taking place within the ICF-MR program.*

- Highly related to the shift from larger to smaller facilities within the ICF-MR program was a trend toward a decreasingly public and increasingly private ICF-MR industry.

- Between June 1977 and 1982 nearly 19,000 private ICF-MR residents were added and the private care of ICF-MR residents increased from 12% to 23%.

- Between June 1982 and 1985 in 40 states the proportion of ICF-MR residents provided for in private facilities increased from 23% to 33%.

• *States vary remarkably in the size and dynamics of their ICF-MR programs.*

- The proportion of total beds in state residential systems that are ICF-MR certified varies substantially across states. In 1982 85% or more of all beds in Minnesota, Rhode Island, Utah, Texas, and Louisiana were certified, compared to 35% or less in Arizona, Florida, Missouri, North Dakota, Virginia and Wyoming. The national average was 58%.

- Twelve states actually decreased their number of occupied ICF-MR beds between 1977 and 1982, largely because population declines in their certified state institutions were not equalled by commensurate private and small public facility certifications. New York and Michigan decreased by about 8,000 ICF-MR beds during the period. Between 1982 and 1985 several other states joined the group with net bed losses. Interestingly New York increased its total ICF-MR population by about 3,500 between 1982 and 1985, primarily through development of small ICF-MR facilities.

-- A number of states significantly increased ICF-MR beds between 1977 and 1982; California and New Jersey alone added over 9,000. However, most of the newly added ICF-MR beds during the period came from the certification of existing large state institutions. With few beds left uncertified in state institutions, the number of ICF-MR covered residents in state institutions is estimated to have declined by 8,000-9,000 between 1982 and 1985.

• *Small ICF-MR facilities are growing rapidly in number, but they tend to be concentrated in a few states.*

-- In mid-1977, three-quarters (74.5%) of small ICF-MR facilities were in Minnesota and Texas. In mid-1982, nearly half (46.4%) of small ICF-MR facilities were in Minnesota and New York; 65.1% were in Minnesota, New York, Michigan and Texas. By mid-1984, half (48.2%) of small ICF-MR facilities were still in Minnesota and New York and 62.0% were in Minnesota, New York, Michigan and Texas.

-- Between June 1982 and 1985, New York, California, and Ohio accounted for about 60% of the total growth in small ICF-MR residents within 40 states.

• *Small (15 or fewer residents) ICF-MR facilities are getting even smaller.*

-- In mid-1977 small ICF-MR facilities had an average population of 9.2.

-- In mid-1982 small ICF-MR facilities had an average population of 8.1.

-- Small ICF-MR facilities opened between January 1981 and June 1982, had an average population of 6.8.

-- In a recent survey a number of state mental retardation agency personnel said that the introduction of the Community and Family Living Amendments has been a factor in the development of smaller ICF-MR residences than might otherwise have occurred.

• *Large and small ICF-MR facilities have similar release rates, but there is a much lower rate of admission to large ICF-MR facilities.*

-- The depopulation of large ICF-MR facilities (16 or more residents) is taking place primarily through rates of release that are similar to those of other types of facilities, but with average rates of new admission that are much lower than those of smaller facilities.

-- There were 275 new admissions per 1,000 total residents in small ICF-MR facilities in FY 1982, but only 60 per 1,000 residents in ICF-MR facilities of 76 or more residents.

• *Population changes among residential facilities are much more highly related to facility size than to certification status.*

-- Resident movement trends in Fiscal Year 1982 among certified and noncertified facilities of the same sizes tended to be quite similar.

-- Differences among size categories within certified and noncertified facilities were large, with major shifts toward increasing the number of people in relatively small facilities (certified and noncertified) and decreasing the number in relatively large facilities.

-- Comparison of certified and noncertified facilities within the same size categories in FY 1982 showed small (15 or fewer residents) ICF-MR facilities to be growing faster than small noncertified facilities (increases in number of residents of 12.1% and 5.7%, respectively) and the very largest ICF-MR facilities (301 or more residents) to be depopulating faster than the very largest noncertified facilities (decreases of 5.9% and 3.2% respectively).

• *An estimated 42,500 (±9,000) persons with a primary diagnosis of mental retardation were residing in nursing homes in 1977 according to the National Nursing Home Survey of 1977.*

-- Of these an estimated 85% (36,100) were in Medicaid certified facilities.

-- An estimated two-thirds had Medicaid as a primary source of payment.

-- An estimated 29,000 of these persons were 62 years or younger; 13,500 63 years or older.

-- An estimated 82% had been a resident of the same nursing home for at least one year previous.

Characteristics of Residents - All Facilities

• *The number of children and youth (persons 21 years and younger) in state mental retardation systems has been decreasing substantially.*

-- While the total residential population was nearly constant between 1977 and 1982, the number of children age 0-21 decreased by more than 30,000 from 91,000 (38.5% of all residents) to 60,000 (24.8% of all residents). The total U.S. population aged 0-21 decreased from 37.5% to 34.5% during the same period.

-- Decreasing numbers of young people in residential facilities were noted in every state. In 1977 the proportion of residents who were 0-21 ranged from 19.7% in Alabama to 69.5% in Alaska; in 1982 from 11.7% in Rhode Island to 50% in Alaska.

- *The relative proportions of mildly, moderately, severely, and profoundly retarded residents in the total residential care system did not change substantially between 1977 and 1982.*
  - -- The proportion of residents who were severely or profoundly mentally retarded increased from 59.7% in 1977 to 60.5% in 1982.
  - -- The proportion of residents who were borderline or mildly retarded was 16.9% in 1977 and 16.8% in 1982.

- *The proportion of residents in small facilities (15 or fewer residents) who were severely or profoundly retarded increased from 23.9% of the total in 1977 to 32.7% in 1982 (from 5,500 to 13,700 individuals).*

- *The most severely handicapped residents continue to be disproportionately placed in large (16 or more residents) public institutions.*
  - -- The proportion of residents in public institutions who were profoundly retarded has increased from 15% in 1939 to 57% in 1982.
  - -- The number of profoundly mentally retarded persons who resided in state institutions increased from 51,000 to 68,000 from 1965-1982.
  - -- In 1982, 25.5% of state institution residents were non-ambulatory, compared to only 19.5% of residents in the total residential care system; 38% of institutionalized residents were not toilet trained compared to 26.7% of residents in the total residential care system. These differences are highly associated with the greater proportion of profoundly retarded people in state institutions.

- *Fewer than 20% of the residents in either public or private residential facilities have extraordinary health care needs.*
  - -- There is no statistically significant difference between the proportions of public facility residents (19%) and private facility residents (17%) with chronic health problems.
  - -- There is no evidence that the medical care needs of public institution residents are substantially different or more extensive than those of persons living in private residential facilities.

Characteristics of Residents - ICF-MR Facilities

- *The number of children in ICF-MR facilities has decreased significantly.*
  - -- In 1977, 4.4% of ICF-MR residents were under 10 years old; by 1982 the proportion dropped to 2.5%.

- In 1977, 35.6% of ICF-MR residents were age 0-21, compared to only 23.6% in 1982.

- The largest ICF-MRs have the lowest proportion of children and youth-- only 21% of residents of ICF-MR facilities with more than 150 residents were under 22 years old.

• *The ICF-MR population is becoming more severely impaired.*

- Between 1977 and 1982 the proportion of ICF-MR residents who were profoundly retarded increased from 44% to 50%, compared to an increase of from 34% to 37% for the service system as a whole.

- In 1-6 bed ICF-MRs, the proportion of residents who were profoundly retarded increased from 3% to 21% between 1977 and 1982. In 7-15 bed ICF-MRs, the increase was from 3.5% to 14%.

- Between 1977 and 1982 the proportion of ICF-MR residents who were mildly/moderately retarded decreased by 3%, although with the growth in the ICF-MR program their actual numbers increased by 5,230 persons.

• *States vary substantially in the characteristics of the residents in their ICF-MR programs.*

- Because there is no specific target population for the ICF-MR program, states have exercised wide latitude in defining their own populations.

- Nationally, 25% of ICF-MR residents in 1982 were mildly or moderately retarded, ranging from under 10% in Hawaii, Maine, and West Virginia to over 37% in Minnesota, Colorado, and Oklahoma. (Since 1982, the proportion of ICF-MR residents who were mildly or moderately retarded has decreased substantially.)

Costs of Residential Services - All facilities

• *Approximately $15.3 billion was spent by all levels of government on behalf of mentally retarded persons in 1982. (Estimated by Inspector General of DHHS, 1983; corroborated by the Expenditure Analysis Project, 1985).*

- An estimated $7.5 billion (49%) were federal expenditures and $7.8 billion (51%) were state and local expenditures.

- An estimated $7.3 billion (48%) were Medicaid long-term care (ICF-MR, SNF, and ICF) and medical assistance expenditures.

- An estimated $5.4 billion (35%) went to state residential care systems and 7-8 billion dollars or about half to mentally retarded persons in all forms of residential care (including nursing and other generic types of facilities not specifically licensed to serve mentally retarded people).

* *Public expenditures for state residential care systems for mentally retarded persons increased from approximately $3.1 billion in 1977 to approximately $5.4 billion in 1982.*

* *The entire increase in expenditures between 1977 and 1982 can be attributed to increases in per diem costs (the number of residents served by the system actually decreased by 1.7% over this period).*

* *While the overall increase in per diem costs was 80.8% for the system between 1977 and 1982, the amount of increase varied substantially by type of facility.*

-- The average per diem cost of small (15 or fewer residents) ICF-MR group residences increased from $21.68 to $64.94.

-- The average per diem of small non-ICF-MR group residences increased from $16.04 to $30.56.

-- The average per diem of large (16 or more residents) ICF-MR group residences increased from $42.94 to $80.49.

-- The average per diem of large non-ICF-MR group residences increased from $33.54 to $45.76.

--The average per diem for foster/family care homes increased from $9.57 to $16.12.

* *The national average per diem rate was $61.89 in 1982, but there was wide variation across states, from Alaska ($117.62) to Montana ($37.73).*

Costs of Residential Services - ICF-MR Facilities

* *ICF-MR (both federal and state expenditures) was the fastest growing component of both state residential care and Medicaid long-term care expenditures.*

-- ICF-MR expenditures increased from 53% of the total cost of state residential care in 1977 to over 75% in 1982.

-- The daily public cost for ICF-MR care increased from about $4.5 million on June 30, 1977 to $11.2 million (150%) on June 30, 1982.

-- Total public expenditures went from $350 million in Fiscal Year 1975 to $3.6 billion in 1982 and an estimated $3.9 billion in 1983 (S. Hrg 98-1045).

-- ICF-MR expenditures represented 30% of all Medicaid long-term care costs in 1982 compared to about 10% in 1975.

- *Early increases in ICF-MR expenditures (pre-1977) were due more to increases in total recipients of care than to increases in per recipient costs.* Increases in ICF-MR expenditures since 1977 have been due primarily to increases in per recipient costs. About 70% of the increase in program costs from 1977 to 1982 can be attributed to increasing per diem costs.

- *Although there are no indications of concern about program size and cost in the public record of "debate" on the authorization of the ICF-MR benefit in 1971, the total beneficiaries and real dollar costs of the contemporary program could have been anticipated.*

    - The legislation was primarily, if not exclusively, focused on upgrading, through the stimulatory promise of FFP, the conditions of public institutions which at the time the legislation was passed housed about 183,000 persons (over 40,000 more than 1982 ICF-MR residents).

    - Between FY 1967 (the year national statistics first indicated state institution depopulation) and FY 1970 (the last year for which statistics would have been available at the time the ICF-MR benefit was being considered), the annual real dollar costs of public institution care ($3,985 per year) were increasing at just under 14%.

    - Projections from such statistics would have estimated per resident real dollar costs by 1982 of about $15,000 per year versus the $11,000 actually observed and total program costs of $2.7 billion versus $1.4 billion actually observed.

- *In cost function analyses, several facility and client characteristics were found to be significantly related to cost* (all statements should be read as "the effects of the other facility type, program, case-mix, or input price variables held constant.")

    - On average, ICF-MRs cost $24.00 per day more than non-ICF-MRs.

    - Government facilities are significantly more expensive than any other form of ownership.

    - For both private ICF-MRs and non-ICF-MRs, individual proprietorships were significantly and substantially less costly than both for-profit and not-for-profit corporate facilities.

    - Group residences (staffed residences providing care, supervision, and training) were the most expensive model of care (more than foster, personal, boarding, or nursing care, and semi-independent living).

    - The higher the proportion of profoundly and severely impaired residents, the higher the costs of both ICF-MR and non-ICF-MR facilities. However, the association between costs and residents' levels of impairment was remarkably weak among ICF-MR facilities and considerably stronger among non-certified facilities.

-- The per diem cost of care varies more by the state the facility is located in than by the facility type, program, case-mix, input price, or reimbursement methods used.

-- The use of inflation indices and the use of peer groupings (e.g., client characteristics, level of staffing) were the only reimbursement variables that could be unambiguously associated with lower costs.

• *Although average reimbursements for services to residents of community-based group residences (facilities with 15 or fewer residents) tend to be substantially below those of state institutions, wherein are housed approximately two thirds of all ICF-MR residents ($38.00 vs. $86.00 in 1982), cautions must be exercised in inferring proportional cost implications from the shift from large institutions to small community residences.*

-- Because institutional facilities generally provide and include in their reported costs more of the total services received by their residents, their average reimbursed costs would tend to be higher than community-based facilities even if the costs of the services offered by both were identical. To respond to the desire for a basis of comparison between institution and community programs, five comprehensive accounting studies within 4 different states since 1979. These have included the costs of "comprehensive services packages" for residents of state institutions and community-based group residences (i.e., residential services, day programs, support services, medical/dental and case management) regardless of whether included in the residential facility costs or those of other agencies.

-- Costs of community based programs were found *on the average* to be 75% to 92% of the costs of state institution costs, with the median difference being 86%. It might be further assumed that increased costs of state administration of more numerous and dispersed programs could make the computed differences even less. On the other hand, as these state institutions continue to depopulate and their fixed costs are spread across fewer residents, higher per resident costs can be anticipated.

Regarding State Responses to the Medicaid Waiver

• *Reviews of the waiver applications and interviews with state agency personnel of states with Medicaid waivers approved by April 1984 showed habilitation and case management have been included in almost every state "waivered services" program.*

-- All 29 states surveyed requested some form of habilitation service (although this was sometimes requested under the general service category of adult day health). Over half the states (17) specifically requested authority to provide habilitation in both residential programs and in separate day training center programs.

-- All but one state requested authorization to provide case management as a Medicaid reimbursable service.

-- Twenty-three states (about 80%) received authority to provide respite care as a waivered service, although states varied considerably in limits on the frequency, duration, and costs of the service and on its eligible recipients (i.e., natural and/or foster care providers).

• *The hypothesis that the waiver authority would lead to significant reduction in the growth of small ICF-MR facilities has not been fully supported by resident totals.*

-- A majority of states with waiver approved by April 1984 indicated in 1986 that the waiver option has caused fewer small ICF-MR facilities to be developed than otherwise would have occurred.

-- Continued development of small ICF-MR facilities in states eligible to develop noncertified alternatives through the waiver option is attributed by state respondents to a number of factors, including general satisfaction with the suitability of the ICF-MR level of care for the persons being placed in it, the need for increased planning time to shift away from a small ICF-MR based residential program strategy, and the cost and beneficiary limits placed on the waiver programs, which limit the amount of federal financing of a state's residential care program.

• *States vary considerably in their ability to use and benefit from the waiver authority* because the program beneficiaries and total program costs have been limited by projections of beneficiaries and costs of ICF-MR services in the absence of the waiver.

-- States vary in their ability to use waiver services in residential care systems because of their varying proportions of residents in ICF-MR certified facilities. In 1982 proportions of state system clients in ICF-MR facilities ranged from (excluding 0% in Arizona and Wyoming) 17% in West Virginia and 18% in North Dakota to 98% in Minnesota, 96% in Louisiana, and 89% in Rhode Island and Texas.

-- States vary substantially in the total and proportional (to state funds) Medicaid funding available to them to provide waiver services. For example, in June 1982 New York was receiving approximately $780,000 per day in federal financial participation (FFP) for ICF-MR programs while California was receiving about $495,000 (although California had 2,000 more people in its total residential system). In June 1982 Rhode Island and West Virginia both had slightly more than 1,000 residents in residential care; Medicaid FFP provided 48% of the total estimated daily costs of Rhode Island's system but only 12% of West Virginia's.

-- Differences in state ability to benefit will be a factor in the effectiveness and the acceptability of any alternative to the ICF-MR program (including a block grant) that links funding under the new program to the extent of state participation in the existing ICF-MR program.

- *Controlled longitudinal studies comparing the differential effects of state institutions and smaller, community-based facilities in producing measured changes in adaptive behavior (i.e., skills of use in socially normative patterns and contexts of daily living) are remarkably few, but they uniformly and strongly favor smaller, more community-based facilities.*

  -- A total of 6 studies were identified, with a total of 350 subjects and 6 month to 4 year follow-up periods.

  -- Findings of superior outcomes in community-based facilities are consistent with contemporary (and commonsensical) theory and practice in habilitation of persons, which suggest that daily living skills are much more likely to be acquired, maintained, and generalized to multiple settings if taught in the natural settings in which those skills are normally performed.

Let me give my interpretation to these statistics. First, as a nation we are progressing steadily toward the only morally and educationally tenable goal for residential services: the physical and, to whatever extent may follow, the social and productive integration of persons with mental retardation and other developmental disabilities. Research and daily demonstration make clear that there is no credible reason today to argue that this goal should not be purposefully pursued as a societal goal. There seems little reason to believe that the trends we have seen in the past 18 years can be leading anywhere but to the eventual elimination of segregated institutions.

Medicaid has been by no means totally absent from these positive changes taking place in residential care. It has led to physical and programmatic improvement in institutions, although we better understand today how very limited these have been in enhancing the dignity, liberty, and potential of the people living in them. A more clearly positive effect of the ICF-MR program has been the substantial movement out of state institutions that ICF-MR regulations impelled as states attempted to meet the living quarters standards. Many people point out that the ICF-MR program operates primarily to support large institutions, but it's also true that recent statistics show that Medicaid funds are gradually being shifted toward community-based programs as states develop small ICF-MR[*] and waiver supported community residences.

In sum one can look at this program and find either good or bad, probably depending on a predisposition. Depending on this predisposition one can probably look at proposed modifications of the existing regulations as a positive or neutral act (it would be hard to see them as negative). As I have looked at the program in recent years I have become more impressed with how hard it is anymore to identify any particular Federal policy evident it. At the origin of the program in 1971, this wasn't the case. It was intended to provide incentives to states for upgrading their public institutions. It was to help defray the costs of operating at least minimally adequate institutions. And it was intended to respond to the growing state practice of placing persons who were mentally retarded in private nursing homes or of certifying state institutions as Skilled Nursing Facilities in order to obtain Medicaid cost-sharing for residential care. In the effort to accomplish these goals, there were and remain many severe shortcomings, but at least what was initially being attempted was clear. But, almost from the issuance of the regulations in 1974, it has been increasingly unclear what this program is intending to do.

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[*] I use the definition of 15 people or fewer as designating a "small home" advisedly, but as per convention. Homes with 15 residents are not really very small and are certainly not very homelike. The term "community facility" is often even more distorted in being applied to any facility that is not a state operated institution.

A program responding to the realities of 1971 (indeed, one might argue more like 1967) has been stretched and twisted over the years in an attempt to cover the dramatically changing realities in services to people with developmental disabilities. When smaller, integrated facilities became recognized as best practice, some states began to create little institutions and reimburse them through Medicaid. (Other states, of course, found Federal funds for community placements in residents' S.S.I. or S.S.D.I. benefits, food stamps, and other entitlements.) Then 5 years ago, when Medicaid costs were deemed too high states with Medicaid accounts were given great freedom to try and lower them through providing alternative services with Medicaid funds. (That this did not lower ICF-MR costs is now quite evident.) As these changes have occurred over the years, states have developed dramatically different Medicaid use patterns. Fifteen years after its enactment there is no ICF-MR program there are 49, and there is no ICF-MR policy there are 51.

One cannot help feeling in looking at this program and in talking to state officials about it, that the availability of Medicaid funds and the various "strategies" to get them has become a major and distorting influence in decisions about the development of residential care systems. States simply vary too much in the number and proportion of their mentally retarded populations covered by Medicaid, in the characteristics of the mentally retarded populations covered, in the total funds received from Medicaid, and in the various services they have managed to cover under Medicaid, to think that this program responds to the needs of any particular group of people.

When the term "beneficiary" is applied to individuals it really rings a little silly. States are the beneficiaries, not individuals. Medicaid monies flowing into states are determined by the nature and characteristics of state policy, not the nature and characteristics of the individual in whose name these reimbursements are provided. The issue this raises about the appropriateness of services is obvious, but there is also an issue of basic fairness. For example, citizens of a state that provides less intensive, more appropriate noncertified residential programs to its mildly and moderately retarded population may subsidize through their federal taxes an ICF-MR level of care for similar populations in a neighboring state. Obviously, too, those states that have heavily participated in the ICF-MR program can much more greatly benefit from the Medicaid waiver. In summary, one cannot argue that the ICF-MR program has prevented states from pursuing the evolving state of the art in residential and related services. But one can and should recognize that it impels no movement in that direction. It may promote minimally adequate custodial care, although frankly Courts have been considerably more demanding than ICF-MR surveyors, but it has done nothing to provide that the best contemporary practices be engaged. This is its shortcoming and it is to this end that reform should be directed.

Almost exactly 10 years ago, a GAO report entitled "Returning the Mentally Disabled to the Community" concluded that, "Although the states are primarily responsible for the care and treatment of the mentally disabled, many of these problems are attributable to 1) Federal programs which provide financial incentives that inhibit the appropriate placement of the mentally disabled and 2) the lack of leadership and action by many Federal agencies whose programs do, could, or should affect community placement." Admittedly conditions and standards of residential care have changed considerably in the past ten years. Nevertheless, the conclusions of this report ring true again today.

What should be done? First, we need a policy. We need a unified policy for services to people who are mentally retarded in the United States. Whether states choose to fund services through ICF-MR certification, through the Medicaid waiver, or through some combination of S.S.I./S.S.D.I. other benefits and state funds, the general welfare and habilitation of persons with developmental disabilities should be of equal interest to the Federal government. Such a policy should cover not just persons in mental retardation facilities, but also those in nursing homes, board and care facilities, county foster care, mental health facilities, and in their own homes. Articulation of such a Federal interest ought to be developed through legislation of the nature of Senator Weicker's Quality Services for Disabled Individuals Act.

Second, a developmental disability policy will be more effective if the critical program aspects of where one lives, what one does during the day, and how one's progress and programs are monitored are integrated. Obviously the degree of such integration is affected by the extent to which there is a unified funding system that bridges without financial prejudice the desireable progressions in independence, integration, and productivity that people with mental retardation can make, for example, from intensively staffed residential settings to semi-independent or supported independent living, or from day activity centers to vocational preparation, and meaningful work. Even then the full promise of such integration can be realized only when case managers are empowered through program options, adequate funding, small case loads, and the best possible training to develop personalized services for persons with developmental disabilities.

Even within the current fiscal context a Federal mechanism can be developed to promote such transition. To do so, it must first establish a set of minimal standards to be met by states participating in the Federal program. The Chafee Amendment represents an example of what such standards should look like. The Amendment is moral, it's to the point, it's habilitatively sound, it shows Federal leadership, and it would facilitate the natural and irrevocable movement toward social enfranchisement of people who are mentally retarded. Second, the Federal government must promote greater equity among states in Federal contributions to the services provided to persons with developmental disabilities, without dictating undesirable program decisions for immediate financial benefit. Senator Bradley's Home and Community-Based Services Improvement Act, as well as Senator Chafee's bill, could help substantially in this regard, but again one would hope within the context of clearly articulated national standards.

Third, an effective Federal program should provide levels of support that have considerable relationship to the nature and extent of disability of the persons for whom the program is being provided. Within the current ICF-MR program this relationship is almost nonexistent. Perhaps this should not be too surprising since essentially the same standards apply to all ICF-MR facilities, but its explanation is not a justification. People with less disability should generally receive less intensive and less costly services (at least over the long term), people with severe/profound disability more. A Federal payment system could be developed on the order of the Diagnostic Related Group to reflect this. Establishment of such groupings for equitable Federal payments would be quite straightforward. The assessment technology to do this is readily available. Such payments would not determine total payment for services to an individual, but the state would supplement Federal payment as needed to carry out the person's program plan.

A payment system which relates an individual's nature and degree of disability to the amount of Federal participation in his/her care could bring improvement in the present system in a number of ways. It would give the Federal government some control over its expenditures other than caps, which would be extremely unfair to some states. It would provide a stable source for funding the most appropriate placement for an individual regardless of its certification status, removing disincentives/creating incentives for placements in less intensive/less costly settings. It would reward efficiencies at the state level dollar for dollar, not 20-50 cents per dollar as under the present cost share arrangement. It could provide a payment for persons in day programs who were not also living in ICF-MR facilities and remove incentives for maintaining people in ICF-MR facilities in order to provide and/or bill day program costs through these facilities. It could remove some of the major differences among states in Federal sharing of the costs of services. It could be readily integrated with the other major sources of funds used for residential and related services for persons with developmental disabilities (especially Supplemental Security Income, Social Security Disability Insurance, and Medicare) to create a unified funding stream.

If we can move in the future to a system that reflects a justifiable national purpose with respect to residential, day, and other support programs, that provides equal Federal interest in the adequacy of programs, irrespective of who is providing them, that more greatly empowers persons most familiar with an individual to make the decisions that determine the kinds of programs and opportunities to be provided, and that makes funds provided on behalf of an individual more reflective of his/her relative needs rather than state funding strategies, we can greatly improve the effectiveness and efficiency of our services system. I have no illusions that such changes will take place soon. On the other hand, the alternative of continuing with a program that is essentially 15 years old and aging rapidly, as more and more severely disabled people show us what they can do when given an integrated, meaningful role in their communities, is not very attractive either. Eventually change will be compelled.

As a member of a respite care family for people with severely disabled children, I would urge you also to ensure that we are, as a nation, making an adequate effort to support natural families in providing, planning, and advocating for their own. And finally, I would urge the Subcommittee to use its tremendous influence to do as much as feasible can be done in the area of prevention (e.g., nutrition, pre- and peri-natal care and counseling, general health education, etc.). These are investments it is simply foolish and irresponsible not to make.

STATEMENT OF DAVID BRADDOCK, PH.D., ASSOCIATE PROFESSOR OF COMMUNITY HEALTH SCIENCES, SCHOOL OF PUBLIC HEALTH, THE UNIVERSITY OF ILLINOIS AT CHICAGO, CHICAGO, IL

Dr. **BRADDOCK.** This is actually indicative of the kind of interdepartmental cooperation you see on college campuses.

Thank you, Mr. Chairman, for the opportunity to be with you today. And in listening to the testimony this morning, I would like to make a few comments with respect to some of the statistics that have been thrown around. And thrown around, I think, is the accurate way to describe it.

I was particularly distraught at the degree to which the Health Care Financing Administration seems to be unaware of the statistics that undergird the ICF/MR Program that it administers. I can share with you today the fact that in our most recent survey at the University of Illinois we have been able to identify 100,412 individuals in State institutions in the United States as of fiscal year 1986—that is the fiscal year that just ended, in the States—on June 30. It continues the 20 consecutive years of annual decline of residents in these institutions.

I can, however, at the same time report to you that in the 3 years since I last testified before this committee on this subject, the proportion of total ICF/MR resources allocated to State institutions has not changed. Seventy-five percent of the total reimbursements associated with the ICF/MR Program in fiscal year 1984 were associated with State institutions, and our figure as of fiscal year 1986 is the same figure.

Moreover, we did a more detailed analysis this time and were able to identify the resources being allocated in settings larger than 15 beds outside institutions. So I would like to stress that some 87 percent of the ICF/MR reimbursements projected by the Federal Government in fiscal year 1986 are associated with placements in facilities of greater than 15 beds. In other words, you have got 75 percent of total ICF/MR funding in the institutions, you have another 12 percent of funding outside those institutions in large—16-bed plus—ICF's/MR ICF/MR's.

What this obviously indicates is that the large congregant care facility is still the programmatic setting of choice with respect to the care of DD people in the United States. And although we find a number of States that have made quite bold strides, including States represented by the Senators that are seated here today, the majority of the American States are struggling with respect to the development of community services in the United States, and they will require the kind of national leadership that this country has been lacking in the last several years with respect to promoting community integration.

I greatly admire Senator Chafee in his work with respect to the community and family living amendments. I think this is an essential step to take in terms of elucidating issues associated with community integration. However, I would like to point out that it has been 15 years since the Federal Government made its initial commitment to reform institutions. It seems that we are as far away from that reformation today as we were some 15 years ago. And I think, like my colleague, Charlie Lakin, that it is time for a substantial redirection of the program.

I would offer to you a very simple idea that could change the direction of the program by simply adjusting the match. Give the States another 5-percent reimbursement if they are willing to provide services in settings of 15 beds or less, or under the waiver program, or if they are willing to move someone from a nursing home, to a 15 bed or less facility, for example. Give them 5 percent less reimbursement if they provide care in an institutional setting.

That simple step would send a clear and convincing signal to the States that, indeed, the Federal Government's money is in the same position that the ideology is.

We have good legislation now in the Developmental Disabilities Act area. It is time, I think, that the Health Care Financing Administration and the legislation that undergirds it and the ICF/MR Program catches up with it.

Thank you.

Senator Durenberger. Thank you, Dr. Braddock.

[The prepared written statement of Dr. Braddock follows:]

STATEMENT ON
MEDICAID AND DEVELOPMENTAL DISABILITIES

of

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Before the

Senate Finance Committee
United States Senate
Washington, D.C.

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STATEMENT OF DAVID BRADDOCK, PH.D. ON MEDICAID AND DEVELOPMENTAL DISABILITIES

Thank you Mr. Chairman for the opportunity to be with you today during these important hearings on the subject of Title XIX services to individuals with mental retardation and related developmental disabilities (MR/DD). My testimony today is divided into two parts, the first of which is an overview of recent trends in the financing of MR/DD services in the United States. The information presented has been collected from the states under the auspices of a database-building grant to the University of Illinois from the Administration on Developmental Disabilities in the United States Department of Health and Human Services. The continuing analysis of the nationwide data is supported by a research grant from the National Institute of Handicapped Research in the U.S. Department of Education. I would like to acknowledge the leadership of DHHS Acting Assistant Secretary for Human Development Services Jean K. Elder, and of Assistant Secretary for Special Education and Rehabilitative Services Madeleine Will in recognizing and supporting the need for continuing public policy research in the developmental disabilities field.

The second part of my testimony will deal specifically with Medicaid issues, but I feel that a more general overview of the financial structure of the MR/DD field is required before specialized information is presented on how the Medicaid Program fits into this context. I stress that the opinions I offer today are strictly my own.

PART I

Overview of the 1986 University of Illinois Study of Public Spending for MR/DD Services in the United States

One important choice faced by state governments today relates to the extent to and manner in which they fund state-operated institutions versus alternative community-based services. The rapid growth of community residences nationally since 1977 (Hauber, Bruininks, Hill, Lakin, Scheerenberger, & White, 1984; Janicki, Mayeda, & Epple, 1983) and the decline in institutional populations (Braddock, Hemp, & Howes, 1986) suggest dramatic changes in how states budget for MR/DD services. However, there is little published research available which tracks state MR/DD spending continuously over a period of many years, although several investigators have underscored the need for the collection and analysis of such data (e.g., Braddock, 1974; 1981; Caiden, 1978; Wieck & Bruininks, 1980).

METHOD

In 1981, a study was launched at the University of Illinois at Chicago which undertook the analysis of every state government's published executive budget from FY 1977 to FY 1984 in terms of MR/DD expenditures. Several publications resulted from that effort (Braddock, 1986a, 1986b, 1986c; Braddock & Fujiura, in press; Braddock & Hemp, 1986; Braddock, Hemp, & Howes, 1984; 1986; in press). The present research extends and expands the original study through FY 1986, and is based on the continuing analysis of state budget documents emanating from the 50 states and the District of Columbia during FY 1985 and FY 1986.

Several operational definitions were also adopted to guide data collection and analysis. Institutional services expenditures were defined as all operating funds appropriated from federal and state sources for state-operated institutions, developmental centers, training centers, state schools, and state psychiatric hospital units for individuals with mental retardation and developmental disabilities. Costs of employees' fringe benefits were included in operating costs. Funds supporting group homes on institutional grounds were considered institutional expenditures.

Community services expenditures comprised federal and state spending, exclusive of educational costs, for the purchase of discrete services from community-based agencies that provided habilitation, day training, residential care, respite, case management, and vocational or related programs, and SSI State Supplement payments. Other community-based mental retardation services expenditures supported regional offices in which state government staff were assigned to oversee or develop community-based services. State-operated group homes not in proximity to institutions and federal/state support for private residential services in settings of all sizes, whether or not they were certified as ICFs/MR, were also considered community service expenditures. Support for mentally retarded persons residing in generic nursing homes, however, was not included in the analysis of expenditures, and, unless specifically noted, federal income maintenance payments were excluded.

The following fiscal classification categories were utilized in the analysis of institutional and community expenditures:

INSTITUTIONAL SERVICES FUNDS

- STATE FUNDS
  - General Funds
  - Other State Funds
- FEDERAL FUNDS
  - Federal ICF/MR
  - Title XX/SSBG Funds
  - Other Federal Funds

COMMUNITY SERVICES FUNDS

- STATE FUNDS
  - General Funds
  - SSI State Supplement
  - Other State Funds
- FEDERAL FUNDS
  - ICF/MR Funds
    - Small Public
    - Small Private
    - Large Private
  - Other Title XIX Funds
    - Title XIX Day Programs
    - Waiver
  - Title XX/SSBG Funds
  - Other Federal Funds

For certain analyses, and as specified below, spending for large 16 + bed privately operated ICFs/MR were included within the institutional services classification category. This produced a new analytical category "Large Congregate Care Facilities."

Analysis

Data were analyzed to identify the presence or absence of trends over FYs 1977-86 with respect to spending for institutional and community services in the states, by facility size and sponsorship, by level of government and by revenue source. Trends were also analyzed with respect to the institutional census, and institutional per diem expenditures were computed for each of the 50 states and the District of Columbia. Per diem expenditures in the states for community care were also computed. This was accomplished after incorporating federal income maintenance payments into the nationwide community spending figures. Two MR/DD prevalence assumptions were utilized: 1.6%, and .287% of the general population. The former rate is a generally accepted estimate of the number of individuals with severe developmental disabilities in the general population (Bruininks & Lakin, 1985), and the latter percentage represents the number of SSI recipients in the U.S. identified in an analysis of a 10% nationwide recipient sample (SSA, 1986). U.S. general population figures were obtained from the Bureau of Economic Analysis (1986a).

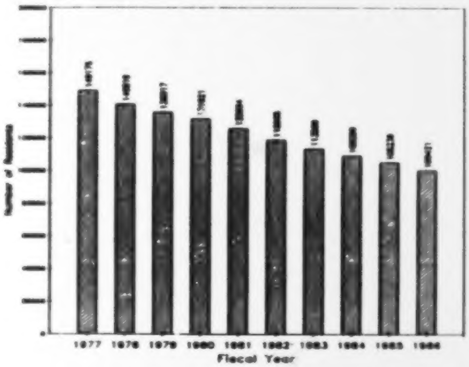
Fiscal effort in the states for FY 1986 was computed by dividing the level of state spending for institutional and community services in a given year by total statewide personal income (Bureau of Economic Analysis, 1983a, 1984, 1986a). All fiscal data were adjusted for inflation using the gross national product implicit price deflator (Bureau of Economic Analysis, 1981, 1983a, 1983b, 1984, 1985, 1986b). Detailed technical notes were prepared for each state describing agency organization, budget document content, and the source of all MR/DD spending figures. State-by-state data were published in a comprehensive publication (Braddock, Hemp, & Fujiura, 1986). A summary of the results of the analysis of nationwide data is presented in this statement.

RESULTS

Institutional Spending

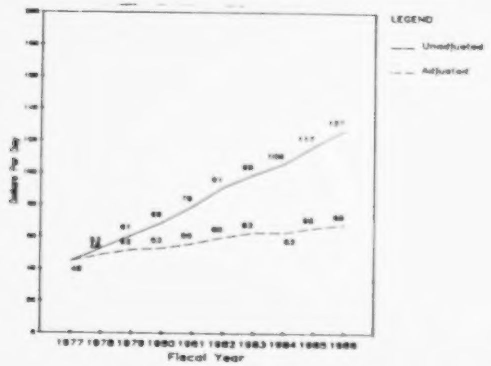
The institutional census continues its steady decline. Between FYs 1977-86, the census declined from 149,176 to 100,421 (Figure 1). This was an average annual decline of 4.30% per year and continued the trend which began in 1967, when the institutional population reached a peak of 194,650 (Lakin, 1979).

Figure 1
Average Daily Residents in Institutions



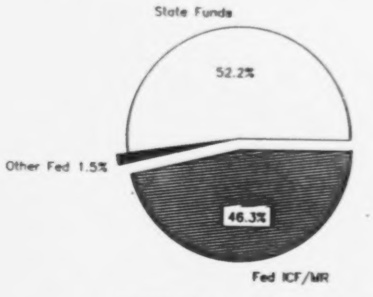
Costs of care in institutional settings climbed from a national average of $44.54 in FY 1977 to $126.79 in FY 1986 (Figure 2). In real economic terms, per diems increased 51.7% (or an annual average of 4.77%) across the decade and grew 6.73% (annually, 3.31%) during FYs 1984-86. Per diems varied widely among the states, ranging from a high of $307.59 in Alaska to $70.13 in Texas. States with per diems in excess of $175/day included Alaska, Arizona, Connecticut, the District of Columbia, Massachusetts, Michigan and New Hampshire; states with per diems below $100/day included Delaware, Indiana, Louisiana, Missouri, Oregon, South Carolina, South Dakota, Tennessee, Texas, Utah, West Virginia and Wyoming. The remaining states had per diems between $100-$175.

Figure 2
Institutional Per Diem Costs: FYs 1977-86



Total spending for institutional operations reached $4.647 billion in FY 1986. In real economic terms, total spending essentially plateaued during FYs 1977-86, and actually declined 4.80% during FYs 1982-84 (average 1.22% per year). Thus, the basic plateauing trend established across FYs 1977-84 noted by Braddock, Hemp, & Howes (1986) has continued through FY 1986. State-source funding for institutions also continued its steady decline on a nationwide basis through FY 1986, while federal funding, primarily ICF/MR revenues, leveled off during FYs 1984-86. In FY 1977, federal ICF/MR reimbursements constituted 24% of total institutional spending and by FY 1986 the percentage had grown to 46%. Figure 3 illustrates institutional revenue sources in FY 1986.

Figure 3
Institutional Revenue Detail



FY 1986 Total Funds: $4.647 Billion

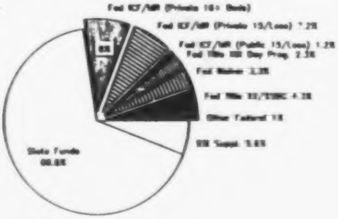
Community Spending

Total spending for community programs nationally continued to climb rapidly, advancing from $.910 billion in FY 1977 to $4.422 billion in FY 1986. These figures, which exclude federal income maintenance payments, but include state supplementation of SSI, represented an average annual growth rate of 19.3%. About two-thirds of the expenditures in FY 1986 derived from state general funds, another 5.9% from state supplementation of SSI, and the remaining 27% from federal ICF/MR reimbursements and the Social Services Block Grant (Figure 4). Real spending for MR/DD services under the SSBG decreased during FYs 1980-86 by 43.3% (average yearly, 8.5%). In contrast, federal ICF/MR reimbursements for community services climbed from $41.273 million in FY 1977 to $728.567 million in FY 1986.

Institutional Bias of ICF/MR Funding

Most ICF/MR reimbursements (87%) were underwriting services in large congregate care facilities with more than 15 beds. In fact, 75% of total ICF/MR funding in FY 1986 was deployed to state-operated institutions. In FY 1977, the percentage of ICF/MR funds devoted to the support of 16+ bed facilities was 98.5%. Federal support provided under the Title XIX Home and Community-based Services Waiver grew from $1.244 million in FY 1982 to $144.623 million in FY 1986, but FY 1986 Waiver funds represented a proportionately small sum when compared to an ICF/MR commitment level of nearly $3 billion. Revenue sources for community services in FY 1986 is presented in Figure 4.

Figure 4
Community Revenue Detail



FY 1986 Total Funds: $4.42 Billion

Community Per Diem Expenditure

Figure 4 above included state supplementation of SSI as community services revenue, but it excluded the substantial income maintenance programs funded by the Federal Government. Collectively, federal SSI payments and Adult Disabled Child Program (ADC) benefits under Social Security (often termed SSDI or "Childhood Disability") contributed $3.02 billion to the maintenance of MR/DD individuals residing outside public institutions in FY 1986 (SSA, 1986). By factoring these federal income maintenance figures into the community revenue totals presented above, a nationwide MR/DD per diem community expenditure for FY 1986 that was roughly comparable to an institutional per diem was derived.

Community per diem spending was computed using two assumptions about the prevalence of MR/DD in the general population (1.6% and .287%). Results are presented in Table 1. The .287% prevalence rate refers to the actual number of MR/DD persons receiving SSI payments in 1985 (686,000). Community per diem spending ranged between $5.33 and $29.70. This was between 4.2% and 23.4% of the actual FY 1986 nationwide institutional per diem of $126.79.

Table 1

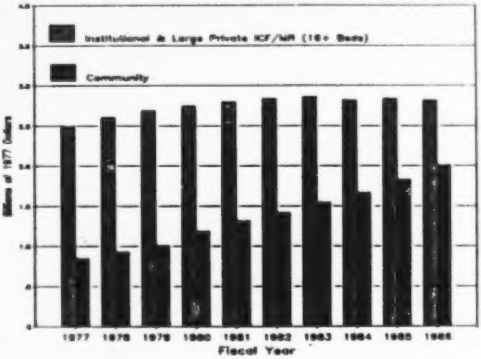
Prevalence Assumption	1985 U.S. Population	Total Community Spending	Community Per Capita
1.6%	239 million	$7.437 billion	$ 5.33
.287%	239 million	$7.437 billion	$29.70

Comparative Analysis of Institutional and Community Spending

Braddock, Hemp, and Howes (1986) previously documented a plateau in adjusted institutional spending nationwide across the FYs 1977-84 period. This trend was unusual historically--a similar trend has not been noted since World War II. On the basis of the FYs 1985-86 data collected in the present study, a gradual decline was discerned in adjusted total institutional spending across FYs 1982-86. In contrast, nationwide spending for community services increased by 42% during FYs 1982-86, and it has increased continuously at a real average annual rate of 11.2% over the past 10 years.

Public resources, however, remain heavily concentrated in large congregate care facilities with more than 15 beds. As illustrated inFigure 5 below, state institutions and large publicly funded privately operated ICF/MR facilities with 16+ beds received the great majority of available resources for MR/DD services over the past decade. Since FY 1983, a gradual decline in public support for large congregate care facilities has been evident, however.

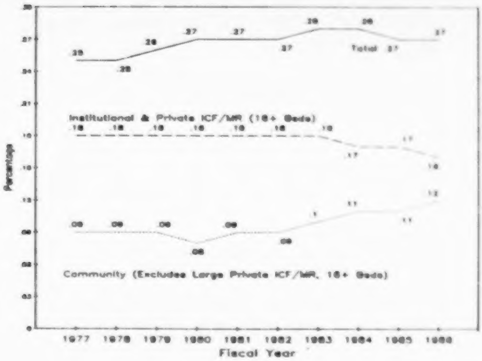
Figure 5
MR/DD Spending for Large Congregate Care, and for "Net" Community Services



Fiscal Effort

As a percentage of aggregate U.S. personal income, total nationwide MR/DD spending was essentially flat during FYs 1983-86, and grew only marginally (12% or an average 1.9% annually) during FYs 1977-83. The overall trend concealed an 11% decline during FYs 1983-86 in total nationwide MR/DD spending for services in large congregate care settings (i.e., in institutions and 16+ bed private facilities). In contrast, a dramatic and continuous climb in nationwide community services fiscal effort, exclusive of 16+ bed ICF/MR facility reimbursements, was noted from FY 1980 through FY 1986. Growth in this "net" community services fiscal effort averaged 10.7% during this seven year period (Figure 6). However, 5 states exhibited a declining level of net community services effort during the FY 1984-86 period: Arkansas, Georgia, Nebraska, Ohio, and Tennessee.

Figure 6
MR/DD Spending as a Percentage of
Personal Income by Facility Size



Continuing consideration of large private ICF/MR facility funding consolidated with institutional expenditures for FY 1986 (i.e. large, congregate care spending), only 13 states expended equivalent or greater sums for the remaining "net" community services they funded. The 13 states which haved reached or exceeded "parity" between large congregate care facility spending and spending for net community services included Alaska, Arizona, California, Colorado, the District of Columbia, Florida, Indiana, Michigan, Montana, Nebraska, New Hampshire, Rhode Island and Vermont.

These 13 states were also highly rated in terms of the fiscal effort they exhibited in financing community services. As indicated by Table 2, regional leaders were identified. Moving from west to east they included California, Colorado, Nebraska, Michigan, Florida, New York, and Vermont. As a region, New England had the most progressive profile in financing community services. Three New England states were among the top 10 in fiscal effort: Vermont, Maine, and New Hampshire. Michigan also continued its rapid transformation from an institution-dominated service system to one dominated by small-scale community-based services.

Fiscal effort rankings in FY 1986 for each of the 50 states and the District of Columbia are presented below in Table 2 for large congregate care services, net community services, and both settings combined. The states' FY 1984 ranking is presented parenthetically. These rankings are based on MR/DD spending levels in the states divided by aggregate statewide personal income.

TABLE 2

MR/DD Spending in FY 1986 & 1984 as a Share of Personal Income, Ranked By State

1986 (1984)	Rank Community - Large Private ICF/MR/ Personal Income	Rank Institutional + Large Private ICF/MR/ Personal Income	Rank Total MR/DD Spending/ Personal Income
RHODE ISLAND	1 (1)	23 (15)	5 (3)
NORTH DAKOTA	2 (18)	1 (1)	1 (4)
DIST OF COLUM	3 (6)	19 (12)	6 (8)
VERMONT	4 (2)	21 (19)	8 (5)
MICHIGAN	5 (7)	47 (39)	16 (20)
NEW HAMPSHIRE	6 (4)	37 (34)	11 (11)
MINNESOTA	7 (5)	8 (2)	2 (2)
NEW YORK	8 (3)	4 (4)	4 (1)
PENNSYLVANIA	9 (9)	14 (9)	10 (7)
MAINE	10 (11)	10 (6)	7 (6)
MONTANA	11 (8)	32 (33)	15 (14)
CONNECTICUT	12 (23)	2 (3)	3 (10)
MASSACHUSETTS	13 (12)	6 (5)	9 (9)
SOUTH DAKOTA	14 (13)	15 (14)	14 (13)
ALASKA	15 (22)	49 (50)	36 (39)
NEBRASKA	16 (10)	38 (29)	25 (17)
WYOMING	17 (19)	11 (11)	13 (12)
CALIFORNIA	18 (15)	40 (41)	32 (32)
WISCONSIN	19 (14)	16 (18)	20 (15)
NEW JERSEY	20 (24)	13 (16)	17 (18)
MARYLAND	21 (25)	39 (38)	30 (35)
GEORGIA	22 (17)	29 (36)	23 (26)
OHIO	23 (16)	27 (25)	22 (22)
IDAHO	24 (20)	33 (31)	28 (24)
COLORADO	25 (21)	44 (43)	40 (36)
LOUISIANA	26 (35)	5 (7)	12 (16)
INDIANA	27 (31)	46 (48)	42 (45)
FLORIDA	28 (30)	48 (47)	45 (44)
WASHINGTON	29 (29)	22 (27)	24 (29)
MISSOURI	30 (26)	41 (46)	43 (43)
DELAWARE	31 (50)	26 (23)	27 (37)
ILLINOIS	32 (27)	35 (30)	35 (31)
ARIZONA	33 (32)	50 (49)	48 (47)
OREGON	34 (37)	28 (20)	31 (28)
SOUTH CAROLINA	35 (36)	7 (10)	18 (21)
NEW MEXICO	36 (33)	34 (26)	38 (33)
UTAH	37 (43)	18 (21)	29 (30)
IOWA	38 (28)	24 (22)	33 (25)
MISSISSIPPI	39 (34)	3 (8)	19 (19)
NORTH CAROLINA	40 (38)	9 (13)	21 (23)
KENTUCKY	41 (44)	45 (44)	47 (48)
KANSAS	42 (40)	20 (24)	34 (34)
ARKANSAS	43 (39)	12 (17)	26 (27)
HAWAII	44 (42)	43 (42)	50 (46)
WEST VIRGINIA	45 (48)	42 (45)	49 (49)
TENNESSEE	46 (41)	30 (37)	41 (42)
NEVADA	47 (49)	51 (51)	51 (51)
ALABAMA	48 (47)	25 (28)	39 (38)
VIRGINIA	49 (45)	31 (35)	44 (41)
TEXAS	50 (46)	36 (32)	46 (40)
OKLAHOMA	51 (51)	17 (40)	37 (50)

DISCUSSION AND CONCLUSION

The single most important budgetary trend evident during FYs 1977-86 was the dramatic growth of spending in the states for community services. In contrast, even though institutional per diems continued to rise, the institutional sector was contracting proportionately with respect to total MR/DD spending, and absolutely when expressed in real economic terms. Excluding federal income maintenance payments, the nation expended 2 1/2 times as much for institutional care in FY 1977 as it did for community services in facilities of all sizes; but in FY 1986, the nation was spending approximately equal sums in both sectors, $4.647 billion vs. $4.422, respectively.

The ICF/MR Program

Services for individuals with mental retardation and developmental disabilities were predominately provided in large congregate care settings. Indeed, a second striking finding of the study was that fully 87% of all federal reimbursements budgeted under the ICF/MR Program in FY 1986 was associated with large 16+ bed congregate care settings. Seventy-five percent of FY 1986 ICF/MR reimbursements supported care in state-operated institutions; and only 9 states were budgeting 25% or more of their total available federal ICF/MR resources in FY 1986 for small 15-bed or less facilities. The states were Alaska (37%), Connecticut (31%), the District of Columbia (48%), Florida (27%), Indiana (44%), Michigan (44%), Minnesota (29%), North Dakota (25%), and Rhode Island (45%). No state budgeted as much as 50% of its total ICF/MR resources for 15-bed or less facilities. The large congregate care facility is the dominant ICF/MR service model being used in the states.

In 1982, Lakin & Hill (1984) identified 9,714 residents of small 15-bed or less ICF/MR funded group homes in the U.S. This was about 7% of all ICF/MR residents served that year. According to our financial data, 7.1% of total ICF/MR expenditures in 1982 were associated with those 9,714 placements. The data gathered in the present study indicated that 13.0% of the money budgeted in the ICF/MR program in FY 1986, or $372 million, was being used to support care in 15 bed-or-less facilities. Imputing from these financial and client data (7.1:9,714 = 13.0:x), we concluded that approximately 17,786 persons resided in small ICFs/MR on June 30, 1986. This is surely indicative of the continuing expansion of smaller scale living environments for MR/DD people under ICF/MR auspices.

The ICF/MR Program was authorized by Public Law 92-223 in 1971. During the first full fiscal year of operation (1972), $36.9 million was budgeted for reimbursements in state-operated institutions. In FY 1986, $2.9 billion was projected by the states for total federal reimbursement ($2.148 billion of which was for reimbursement of state institutions) and the states themselves provided another $2.3 billion in matching funds. Thus, this single federal program was directly responsible for $5.2 billion in state-federal MR/DD expenditures, and this sum represented one-third of total annual public (federal, state, local) spending for MR/DD activities in the United States (Braddock & Hemp, 1986).

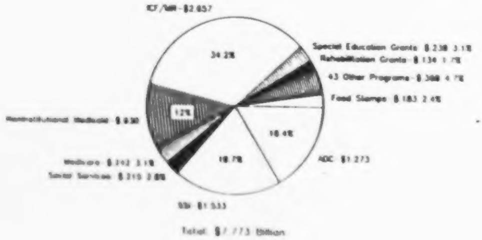
Although ICF/MR support for care in state-operated institutions is widely recognized to be extensive, e.g. Hill & Lakin (1984), it is surprising that so much of the Program's resources (75%) was associated with an activity, which, prior to P.L. 92-223's enactment in 1971, was solely the responsibility of the states. In a hierarchical multiple regression analysis, Braddock and Fujiura (in press) recently found a strong inverse relationship (Beta coefficient = -.653) between the extent of federal ICF/MR support and state funding for institutions. In other words: the more money spent by the Federal Government to support institutions, the less being spent by the states. Given the potentially much larger constituencies for MR/DD services existing outside state-operated institutions (Table 1), and the continuing and inexorable decline of the institutional census, the contemporary budgeting of ICF/MR reimbursements predominantly inside institutions would seem to be an anachronism.

PART II: MEDICAID ISSUES IN DEVELOPMENTAL DISABILITIES

I would now like to focus specifically on the Medicaid Program. The foregoing overview has characterized the central importance of the Medicaid Program in the states, particularly the ICF/MR Program, but it has not examined in sufficient detail the role of the Medicaid Program in the total mix of Federal assistance for MR/DD persons.

Figure 7 below illustrates Federal Government funding for MR/DD programs in FY 1985. ICF/MR reimbursements constituted fully one-third of total federal spending commitments--making this program easily the single largest source of federal MR/DD assistance. Federal ICF/MR funding accounts for roughly three-fourths of all federal MR/DD funding for services.

Figure 7
Federal MR/DD Spending by Program
in FY 1985 (dollars in billions)



When I appeared before this Committee on February 27, 1983, to offer testimony on the Community and Family Living Amendments, I pointed out that 75% of all Federal ICF/MR reimbursements that year was associated with the support of placements in state-operated institutions. I am saddened to report to you today that some three years later in FY 1986, 75% of total Federal ICF/MR reimbursements is still being deployed to state institutions. There has been no change on a national basis in terms of the "institutional bias" of the ICF/MR program. An additional 12% of total ICF/MR support in FY 1986 was also associated with placements in privately-operated large congregate care facilities with 16+ beds. Thus, 87% of ICF/MR funding is concerned with placements in large 16+ bed congregate care facilities. Only 13% of Federal ICF/MR spending-- or $373 million in FY 1986--was associated with placements in smaller facilities of 15-beds or less. Even though the number of placements in these smaller-scale facilities is growing steadily, only about 17,786 of the approximately 141,000 recipients served in the ICF/MR Program resided in these 15-bed or less facilities in FY 1986.

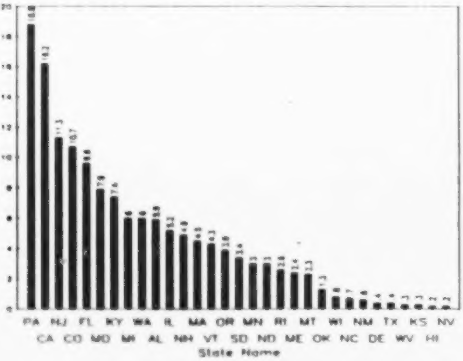
I must stress that the Federal ICF/MR Program accounts for 3/4 of all Federal funding for MR/DD services, and barring any purposive redirection of institutional ICF/MR reimbursements to smaller scale community alternatives, it will be a very long time before a majority of the nation's ICF/MR residents have the opportunity to live in family-scale community based living facilities. I would therefore urge the Committee to consider adopting a higher match for states promoting the establishment of 15-bed or less residential alternatives and Waiver sponsored services, and a correspondingly lower match for states electing to use federal funds to underwrite institutional care.

Institutional care until 1971 was a state responsibility. Does the Federal Government, which is now underwriting one-half of the total costs of MR/DD institutional care in the states, intend to permanently accept such responsibility for the nations 240+ state institutions? Or should not a state that wishes to finance placements in institutional environments be required to pay for these services fully out of the state's tax base? Why should the citizens of Maine, Minnesota, Michigan and Montana, states which stress appropriate family-scale community living environments, be expected to underwrite institutional care in Texas and Alabama? They should not be expected to do so. Over a responsible period of time, the Federal Government should gradually phase-down it's support of state institutions, and rebudget those resources toward family-scale, family-empowering community care objectives.

Home and Community-Based Waiver

The Section 2176 Medicaid Waiver Program, originally authorized by the Omnibus Budget Reconciliation Act of 1981, is making an extremely important contribution to the development of community services in the United States. As shown below in Figure 8, 31 states in FY 1986 anticipated federal reimbursements of some $144 million, and several thousand clients have benefitted from this special program offered by the states. This Committee should be commended for the recent action it took in extending and expanding the Waiver Program through the Consolidated Omnibus Reconciliation Act of 1985 (COBRA). But we must not lose sight of the fact that compared to the volume of Title XIX ICF/MR funds devoted to congregate care institutions and large private facilities. Waiver funding is miniscule; and it is exceedingly complex for states and community agencies to obtain Waiver funds. This Committee might consider an amendment to Title XIX whereby ICF/MR funds supporting MR/DD services *in state institutions and* large private facilities might be rebudgeted under Section 2176 to enhance home and community based waiver services. The states could easily and responsibly spend much greater sums of money than are now being budgeted under the Waiver Program. Simplified guidelines need to be adopted for or by the HCFA to expedite the rebudgeting of ICF/MR funding in the states toward Waiver Program objectives.

Figure 8
Waiver Reimbursements in 31 States During FY 1986



Medicaid Community Health Care Services for MR/DD Persons (Medical Assistance)

Public Law 89-97 authorized the Medicaid medical assistance program in 1965. This legislation broke radically with the early tradition of the Social Security Act, which had forbade Federal support for such assistance. Under this program, states must provide services to "categorically needy" public assistance recipients, and may provide services to "medically needy" persons. Services provided include in-patient and out-patient hospital services, other laboratory and x-ray services, skilled nursing home services, home health services, family planning services, and physician services. The Federal Government reimburses states for between 50% and 77% of the total approved cost of providing services to eligible individuals.

Most individuals with developmental disabilities reside in community settings (including the family home), and many of these persons are eligible for and receive medical assistance under the Medicaid Program.

Eligibility criteria vary from state-to-state, but in general, an individuals is automatically categorically eligible if he or she meets stipulated poverty guidelines, or is currently receiving public assistance such as SSI. Many states also define a "medically needy" category, which broadens eligibility to include certain "non-poor" (those not receiving public assistance) who have significant medical bills. On the other hand, 15 states have more restrictive eligibility criteria for Medicaid than they do for SSI.

Precise nationwide data are unavailable on the extent to which MR/DD persons participate in the Medicaid Medical Assistance Program. However, that participation is extensive, given available SSI data documenting the MR/DD participation rates for "blind and disabled" SSI recipients. If we assume that roughly 25% of all blind and disabled SSI recipients are persons with MR/DD (the Social Security Administration recently indicated a more precise figure of 27.42%), an estimated $.929 billion in Medicaid reimbursements for MR/DD individuals was budgeted in FY 1985 (Braddock, 1986a). This is an extremely important program for MR/DD persons and their families. I encourage the Committee to support policies that will enable MR/DD individuals in supported and competitive employment to continue receiving medical assistance for an extended period of time, and in some cases, permanently.

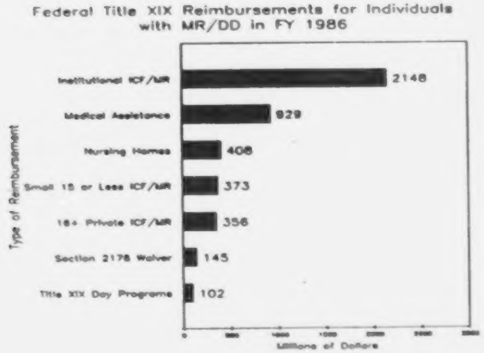
Inappropriate MR/DD Placements in Nursing Homes

One of the major problems with the Title XIX Program is that it provides support for an estimated 50,000 MR/DD residents who are inappropriately placed in nursing homes (General ICFs). (The actual number will be confirmed by national survey later this year. DHHS data in 1977 indicated that there were 79,800 MR/DD residents of nursing homes.) A number of states responded to the calls for deinstitutionalization in the 1960s and 1970s by relocating large number of institutionalized clients to nursing homes. Most clients lacked medical conditions requiring such care, however.

The DD Council in Wisconsin has identified 4,100 inappropriately placed MR/DD persons in Wisconsin's nursing homes. The number in Illinois is approximately equivalent to this figure and Indiana has identified over 2,000 such clients. In Wisconsin, $225 million was expended in FY 1986 for MR/DD residential and supportive services, including nursing care costs. About $165 million of these funds was associated with large congregate care placements in state institutions, large 16+ bed ICFs/MR, and nursing homes. Only $60 million was associated with placement in family-scale community-based services. Like the ICF/MR Program, Title XIX ICF services drives state MR/DD service systems toward large congregate care options. Assuming a public nursing home per diem of $40/day, the Medicaid Program will pay out an estimated $408 million in federal funds in FY 1986 for inappropriate MR/DD nursing home placements (50,000 x $40 x 365 days x 56% federal share).

Figure 9 below illustrates major MR/DD funding streams associated with the Medicaid Program. Note the scale of the ICF/MR Program when compared to Community Health Care Services (Medical Assistance), Nursing Home Care, Day Services, and the Waiver Program. A large but unknown percentage of the Community Health Care and Day Services expenditures are associated with MR/DD clients who reside in large 16+ bed privately operated ICF/MR facilities or nursing homes.

Figure 9
Federal Title XIX Reimbursements for Individuals with MR/DD
(dollars in millions)



Summary and Conclusion

In 1854, President Franklin Pierce vetoed a bill, championed by Dorthea Dix, to set aside 10 million acres of federal land for the care of persons with mental disabilities. Congress was unable to override the veto and for 117 years thereafter, institutional care of MR/DD individuals was totally a state government responsiblity. In the early 1970s, the Federal Government, acting as the conscience of a concerned nation, vigorously responded to the deplorable conditions in so many of this nation's MR/DD institutions, and authorized aid to institutions under the auspices of the ICF/MR Program. There followed a decade of unprecedented growth in federal financing of institutional care. By the early 1980s, the Federal Government was underwriting nearly one-half of the total costs of care in the states' MR/DD institutions. Combined state-federal ICF/MR spending reached $5.2 billion in FY 1986, and represented one-third of all public MR/DD spending, by federal, state, and local units of government. Federal ICF/MR funding of $2.9 billion in FY 1986 represented three-fourths of all federal MR/DD financial assistance for services and 75% of all ICF/MR funds were deployed to underwrite institutional care. There has been virtually no change in the past three years in the proportion of total ICF/MR reimbursements allocated for institutional care. The ICF/MR Program thus continues its strong institutional bias even though many states have begun aggressive community services development campaigns.

I recommend that the Committee envigorate former President Richard M. Nixon's 1971 White House Goal in the area of community integration. President Nixon's objective of "returning more than one-third of the nation's 200,000 residents of public institutions to the nation's communities" has been achieved only in a sheer physical sense; most of the placements out of institutions during the last 15 years were made to large congregate care facilities such as nursing homes and large private 16+ bed ICFs/MR. I suggest that the Finance Committee statutorily adopt a national community integration policy associated with a) all MR/DD residents inappropriately residing in nursing homes; b) the remaining 100,431 residents of state-operated institutions; c) all residents of large 16+ bed privately-operated ICFs/MR, and d) all potential residents of these large congregate care environments.

I am suggesting the adoption of an explicit national priority in community integration, possibly in the form of legislative language stipulated in the pending reconciliation bill. The language should stipulate that the federal matching share be elevated by 5 percentage points in those instances where states' establish 15-bed or less ICF/MR placements for MR/DD residents of state institutions, nursing homes, or large 16+ bed private ICFs/MR. I am also suggesting a dramatic simplification of Waiver policies toward MR/DD clients in one of the above listed priority areas. In a fiscally contervailing action, the federal ICF/MR match for supporting MR/DD placements in state-operated institutions would be reduced by 5 percentage points. In short, I believe that it is time for the Federal Government to send a clear and convincing signal to the states that it is thoroughly committed to family-scale community-based services for MR/DD people in this country. Thank you again for the opportunity to testify on these important issues.

REFERENCES

Braddock, D. (1974). Federal funds--a policy study. In J. Wortis (Ed.), *Mental retardation and developmental disabilities: An annual review*, Vol. VI, pp. 107-146. New York: Brunner-Mazel.

Braddock, D. (1981). Deinstitutionalization of the retarded: Trends in public policy. *Hospital and Community Psychiatry*, *32*(9), 607-615.

Braddock, D. (1986a). From Roosevelt to Reagan: Federal spending for mental retardation and developmental disabilities. *American Journal of Mental Deficiency*, *90*(5), 479-489.

Braddock, D. (1986b). Financing mental retardation programs in the United States. In the *1986 Annual Report to the President*. Washington, DC: President's Committee on Mental Retardation.

Braddock, D. (1986c). *Federal policy toward mental retardation and developmental disabilities*. Baltimore: Brookes Publishing Company.

Braddock, D. & Fujiura, G. (in press). State government financial effort in mental retardation. *American Journal of Mental Deficiency*.

Braddock, D. & Hemp, R. (1986). Governmental spending for mental retardation and developmental disabilities in the United States. *Hospital and Community Psychiatry*, *37*(7), 702-707.

Braddock, D., Hemp, R., & Fujiura, G. (1986). *Public expenditures for mental retardation and developmental disabilities in the United States: State profiles (Second edition)*. Chicago: Institute for the Study of Developmental Disabilities, University of Illinois at Chicago.

Braddock, D., Hemp, R., & Howes, R. (1984). *Public expenditures for mental retardation and developmental disabilities in the United States: State profiles (First edition)*. Chicago: Institute for the Study of Developmental Disabilities, University of Illinois at Chicago.

Braddock, D., Hemp, R., & Howes, R. (1986). Direct costs of institutional care in the United States. *Mental Retardation*, *24*(1), 9-17.

Braddock, D., Hemp, R., & Howes, R. (in press). Financing community services in the United States. *Mental Retardation*, December, 1986.

Bruininks, R. & Lakin, K.C. (1985). *Living and learning in the least restrictive environment*. Baltimore: Paul H. Brooks Publishing Company.

Bureau of Economic Analysis. (1981, July). *The national income and product accounts*. Washington, D.C.: U.S. Department of Commerce.

Bureau of Economic Analysis. (1983a, July). *Survey of current business*. Washington, D.C.: U.S. Department of Commerce.

Bureau of Economic Analysis. (1983b, July). *The national income and product accounts*. Washington, D.C.: U.S. Department of Commerce.

Bureau of Economic Analysis. (1984, April). *Survey of current business*. Washington, D.C.: U.S. Department of Commerce.

Bureau of Economic Analysis. (1985, May). *Survey of current business*. Washington, D.C.: U.S. Department of Commerce.

Bureau of Economic Analysis. (1986a, May). *United States Department of Commerce News*. Washington, D.C.: The Department.

Bureau of Economic Analysis. (1986b) *Survey of current business*. Washington, D.C.: U.S. Department of Commerce.

Caiden, N. (1978). *Collection of data on public expenditure for care of the mentally disabled*. Washington, DC: American Bar Association, Division of Public Service Activities.

Easton, D. (1965). *A framework for political analysis*. Englewood Cliffs, NJ: Prentice-Hall.

Hauber, F., Bruininks, R., Hill, B., Lakin, K., Scheerenberger, R., White, C. (1984). National census of residential facilities: A 1982 profile of facilities and residents. *American Journal of Mental Deficiency*, *89*, 236-245.

Lakin, K.C. & Hill, B.K. (1984). *Expansion of the Medicaid ICF/MR program over a five-year period, 1977-82 (Working Paper 25*. Minneapolis: Center for Residential and Community Services, University of Minnesota, Department of Educational Psychology.

Janicki, M., Mayeda, T., Epple, W. (1983). Availability of group homes for persons with mental retardation in the United States. *Mental Retardation*, *21*,2, 45-51.

Lakin, K. C. (1979). *Demographic studies of residential facilities for the mentally retarded: An historical review of methodologies and findings*. Minneapolis: Department of Psychoeducational Studies.

Natchez, P.B. & Bupp, I. (1973). Policy and priority in the budgetary process. *American Political Science Review*, *67*, 951-963.

Social Security Administration. (1986). Correspondence from Rhoda M.G. Davis, Associate Commissioner, Office of Supplemental Security Income, Social Security Administration, to David Braddock, August 26, 1986.

Wieck, C., & Bruininks, R. (1980). *The cost of public and community residential care for mentally retarded people in the United States*. Minneapolis: University of Minnesota, Developmental Disabilities Project on Residential Services and Community Adjustment, Department of Psycheducational Studies.

Wildavsky, A. (1975). *The politics of the budgetary process, 2nd edition*. Boston: Little, Brown, and Company.

Senator Durenberger. James Conroy.

STATEMENT OF JAMES W. CONROY, DIRECTOR OF RESEARCH AND PROGRAM EVALUATION, DEVELOPMENTAL DISABILITIES CENTER, TEMPLE UNIVERSITY, PHILADELPHIA, PA

Mr. Conroy. Good morning, Senators. I would also like to thank you for this opportunity and thank you for your interest in people with disabilities.

As I interpret the committee's interest, one of the central questions must be: Do large congregate care settings benefit people with mental retardation as much as smaller and more integrated community based settings? I and my colleagues at Temple University have had the pleasure and the honor of studying that question for 8 years now: 5 years with funding from the Office of Human Development Services, and 3 more years with State support as a monitoring activity. We are now engaged in quality assurance in the community programs.

This research project was one of the largest ever supported by the Government on this topic. We found in 5 years of federally financed research, and in 3 more recent years of State financed monitoring on the Pennhurst situation, that people are much better off having left Pennhurst. They are better off than they were at Pennhurst in every way we measured. We used quite a large number of measures because "better off" has many meanings.

People are better off in two important areas that I will mention: First, in terms of their own individual growth and development. The key words in much of the legislation are "achievement of potential," and these people have gained skills in ways we could not have imagined 10 years ago. They are doing more for themselves now than was thought possible.

A second key area is the families, who were originally overwhelmingly opposed to the movement of their relatives. As we know, the families of people in institutions do not want their relatives to move to these new community settings. Among the families of people in institutions across this Nation, and in the Pennhurst situation, well over 70 percent will oppose any movement of their relatives out of those institutions.

In the Pennhurst study, we were able to study what happened when there was little or no family choice. There was a Federal court order for all people to move. Now I can report to you that after it's happened, the families are astounded, surprised, and delighted. Over 90 percent are pleased with the move. In our research, under 3 percent of the families—each year we go out and survey every family every year—are strongly dissatisfied with the community situation. That is quite different from the picture before. The change is the largest I have had the opportunity to witness in social sciences.

We have now been able to perform similar work in Louisiana and in New Hampshire with strikingly similar results. Work is in progress in Colorado, Texas, and Connecticut. We will have answers there within the next few years. So I think the scientific case is coming to a close. We consistently find people in community settings benefiting more than their peers in institutional settings, and they are receiving as much, or more, service, and they are getting these benefits at equal or lower total social cost.

Senator **Chafee**. Just one interruption. You used the term "social cost." What does "social" mean there?

Mr. **Conroy**. What I mean by that is that we went through a great deal of effort to track down every public dollar spent for people in the institutions and for people in the communities.

Senator **Chafee**. So it is lower cost, period?

Mr. **Conroy**. Yes. But we are throwing in everything—State, local, Federal—and we put it all together. Total cost was less in the Pennhurst situation for people in communities.

I must add though that the reason for that was an inequity in staff salaries. People who work in community settings get paid much less for very similar work. That is not fair and that must not continue in our States either.

Possibly the most remarkable finding, in my opinion, of our work is about the question, who benefits the most from this new mode of care? In our research in three States thus far, the results are consistent. It is people labeled "severely and profoundly retarded" who proportionately gain the most in their ability to care for themselves.

Now in Pennhurst, these people are now an average of 45 years old. They lived at Pennhurst an average of 24 years. Eighty-six percent of them were labeled "severely or profoundly retarded," and these are the people who are now out and have benefited so measurably and so greatly.

These findings are strong evidence that Federal funds available would be better spent in these community based settings. We would have to recommend that using Medicaid funds in community settings be made much easier.

Thank you, Senators.

Senator **Durenberger**. Thank you very much, Mr. Conroy. Dr. Mank?

[The prepared written statement of Mr. Conroy follows:]

Results of the Pennhurst Longitudinal Study

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Introduction

For more than a century now, states have maintained large, segregated, isolated, congregate care institutions for people with mental retardation; in the Pennhurst Longitudinal Study we have investigated whether people were better off, in terms of their own individual behavioral development, after leaving such a setting.

The places to which the people went were, in this case, called Community Living Arrangements (CLAs). These were very small programs, usually housing 3 residents but no more than 6, almost always in regular residential housing stock, with constant staffing when the people who live there were present, and which every person left every weekday to go to some variety of day program or work or school. Staff coverage was provided either by the live-in plus part-time-help model or the shift model, with the preponderance of programs using the shift model. Service providers were private entities, about 90% are non-profit, and they ranged from very small (1 CLA site) to quite large (40 CLA sites).

Beyond this basic CLA model, which had been in place in Pennsylvania since the early 1970s, there were certain extra elements that were required by the Federal court for Pennhurst Classmembers. The court mandated Case Managers with caseloads not to exceed 30, ordered that Individual Habilitation Plans (IHPs) be written in a collaborative way involving all concerned professionals and nonprofessionals, and also that those plans be reviewed and approved by a special unit before implementation, and finally that a special unit monitor the well being of the people and the services rendered to them.

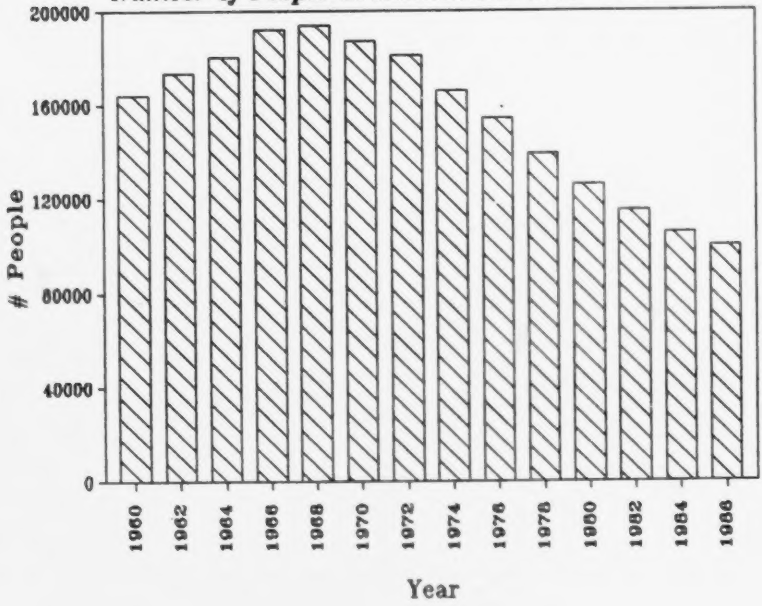
Community service settings similar to these have been proliferating rapidly across the country. But to the extent that a given state's community services differs from the model above, the power to generalize from our Pennhurst Study findings to that state is decreased. As an extreme example, for a state in which the "community service system" is composed of 15-bed, specially constructed or renovated facilities located in mixed zoning areas, our research would probably have little to say.

The deinstitutionalization of Pennhurst should be seen in the national context of declining institutional populations and increasing community residential facility populations. There has been a strong trend away from institutional care, but as of this writing about 100,000 people still live in public institutions. The general trend is depicted in Figure 1.

Insert Figure 1 Here

FIGURE 1

Number of People in Institutions 1960–1986



Whether it would be possible to serve those people in a "better" way, at the same or lower public cost, is the essential question addressed by the Pennhurst Study.

In the sense of Campbell (1967) in his classic article "Reforms as Experiments," the Pennhurst Study was an evaluation of a social experiment. The reform (experiment) in this case was conducted by a Federal court; on March 17, 1978, Judge Raymond J. Broderick of the Federal court for the eastern district of Pennsylvania ordered that all the people living at Pennhurst (among others) move to CLAs. Evidence and expert testimony had convinced the judge that people would be better off, but no one was really certain. In fact, the whole of American society was unsure about this issue of deinstitutionalization.

Prior research had established firmly that deinstitutionalization of people with mental illness had been a national disgrace (Bassuk & Gerson, 1978). In the field of mental illness, the decline in institutional populations began in 1955 (long before it began in mental retardation). People had been "released" from mental institutions with no places to go in the communities, no backups, no supports, and nothing to do during the day. The bulk of public knowledge and beliefs about deinstitutionalization comes from that arena. The politicians who voice concern about the homeless, the street people, and the vent people, are talking about people who were released from mental health, not mental retardation, institutions.

Institutions for people with mental health problems were generally not very pleasant places to live during the 1950s (Goffman, 1961). Public and professional outrage over institutional conditions surely lent momentum to the trend toward institutional discharges. Perhaps an even more powerful catalyst was the development of powerful new medications that could ameliorate the effects of many forms of mental illness. The first of these medications were approved for general use by the Food & Drug Administration in, not coincidentally, 1955. It appears that many people were released from facilities with a supply of medications and little else.

In the field of mental retardation, in contrast, it simply is not possible to construct a parallel situation. When a person with serious intellectual impairment is considered for release, it is clear to everyone that the individual will still need round the clock supervision. There are no chemical or other substitutes for creation of a place to live with staff and therapeutic activities.

Thus the Pennhurst Study was not revisiting an old question; the question became new and different when the people involved had, not mental illness, but mental retardation. The question was, in Pennsylvania, under this court order, at this time, with these Pennhurst residents who had mental retardation, would community placement (deinstitutionalization) be beneficial?

The Human Impacts of This Deinstitutionalization

The part of the Pennhurst Study that was conducted by the Temple University Developmental Disabilities Center/UAF was designed to answer just one question: are people better off? That question has been approached in several ways, because well-being has many measures.

Before presenting the summarized findings about the aspects of well-being that we have measured, we must give brief descriptions of the kinds of people who lived at Pennhurst, and of the kinds of community programs that later became their new homes. Without knowing the characteristics of the people and the system we have studied, one cannot judge whether the results of deinstitutionalization for other people in other systems will be similar to ours.

There were 1154 people who lived at Pennhurst Center on March 17, 1978. Their average age was 39 years, they had lived at Pennhurst for an average of 24 years, and 64% were male; 33% had a history of seizures, 13% had visual impairments, 4% had hearing impairments, and 18% were unable to walk. Life-threatening medical conditions were reported for fewer than 1%. Just over 50% were nonverbal, 47% were less than fully toilet trained, and 40% were reported to display physical violence toward others. Among the people at Pennhurst, 86% were labeled severely or profoundly retarded.

The community service system was composed of residences called Community Living Arrangements, or CLAs. They were very small, with the vast majority serving three individuals. They were almost always located in regular housing stock, and were staffed continuously when the residents were home. All were operated by private service providers under contract with county mental retardation programs, and counties received 100% state support for the residential settings and 90% support for day programs. Every person left the CLA on weekdays to attend a day program.

Individual Behavioral Development

Continual behavioral growth toward reduced dependence is a central goal of services for people with mental retardation. We have found, by every scientific design and test available to us, that people who have gone to CLAs are better off in this regard. They have made more progress than similar people still at Pennhurst, and more than they themselves made during their prior time at Pennhurst. These people have become more able to do things for themselves, rather than having things done for them. "Adaptive behavior" is a general term for this facet of independent functioning. The graph in Figure 2 shows the increases in adaptive behavior for 176 people who were living at Pennhurst in 1978 and 1980, and then in CLAs in 1983 and 1984.

Insert Figure 2 Here

The Behavior Development Survey, or BDS, our general measure of adaptive behavior, could range from 0 to 128 points. From 1978 to 1980, while living at Pennhurst, these people showed no significant increase in adaptive behavior. When they moved to CLAs they became sharply less dependent, and, considering the results of all our analyses, they generally continued to grow and learn after moving, at least for another year.

The final year of data, however, contains the suggestion that the rapid rates of behavioral progress have begun to level off. Evidence thus far is not sufficient to determine the cause; it could be that the system and its service providers simply could not sustain the high level of enthusiasm associated with such an unprecented deinstitutionalization forever, or it might be related to the removal of the special independent court master, or perhaps real progress is still occurring but it is now in areas that our behavioral instrument addresses only slightly (such as self image or comfort in integrated settings or specific vocationally oriented skills). In any case, progress has not stopped or reversed, it merely appears to have slowed.

We also find that the people who seem to make the greatest gains in adaptive behavior tend to be those who start out lowest. That is, the people with the most severe impairments turn out to be among those who benefit the most from community placement.

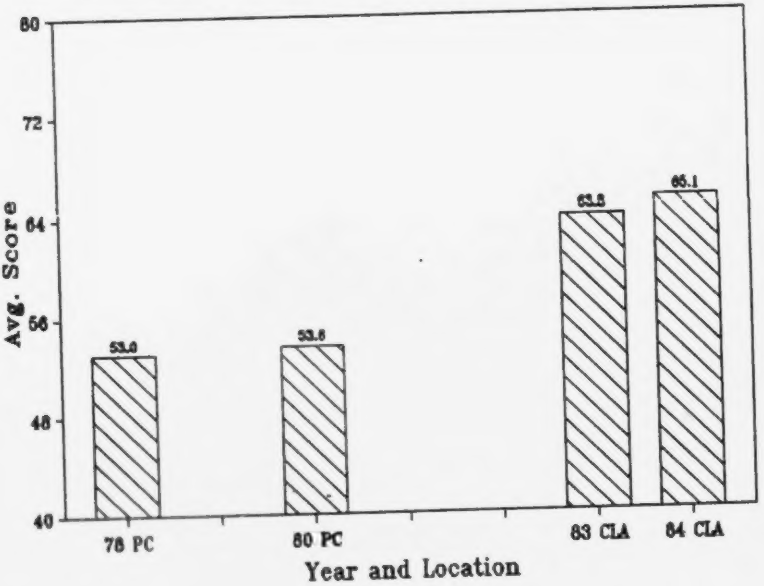
The adaptive behavior growth displayed by people who have moved to CLAs under this court order is literally 10 times greater than the growth displayed by matched people who are still at Pennhurst. People at Pennhurst are not regressing -- they are showing developmental gains, but at a far slower rate than people who move to community placements.

Services Rendered

Do people receive the services they need after community placement? In the Pennhurst situation, there is a change in service patterns when people move to CLAs. The movers receive fewer hours of developmentally oriented service hours at the places where they live (about 104 hours

FIGURE 2

Adaptive Behavior Growth, Before and After Placement



per month compared to about 156 hours among stayers), but more day program service (about 121 hours per month compared to the stayers' 33 hours). Adding the two kinds of service, the movers receive more total hours of service (225 hours per month) than the stayers (189 hours per month). Hence we conclude that, on an overall index of amount of service, the movers are better off.

The evidence on medical services suggests that people in CLAs are, for the most part, using the Medicaid and Medicare services systems effectively, and we have observed few cases of people lacking regular checkups or other needed services. Moreover, we have seen no change in general indicators of individual health following placement.

We also find that the number of daily prescription medications given to each person declines after community placement, and has also declined among the stayers. For both groups, then, we would infer that they are better off in terms of the risk of overuse of medications.

Preliminary Matched Comparison Study

Early in the study, the Temple University part of the research team conducted a small and preliminary comparative costs analysis. We had 1978 and 1980 behavioral and services data for the first 70 people who went to CLAs. For each of the 70 people who moved to CLAs, we identified a person who was still at Pennhurst, and was the same sex, the same level of retardation, about the same I.Q., about the same on our measure of adaptive behavior, and about the same age.

We then attempted to identify every public dollar expended for each mover and each stayer. The areas of cost covered were residential, day program (including transportation where applicable), entitlements/public assistance payments such as SSI, case management, and medical care. This matched comparison analysis was an advance over prior comparative cost studies, because of the matching of people and because we were careful to assess all major public costs rather than just some, but it was by no means as complete as the work to come later by the Human Services Research Institute. In this small study, we found that:

(1) The people who moved to CLAs had improved significantly in adaptive behavior, while the people still at Pennhurst had not.
(2) The people who moved to CLAs were receiving more total hours of developmentally oriented, planned, structured service each week than their matched peers at the institution.
(3) The total public cost of serving the people who moved to CLAs was significantly less than for the matched

people still at Pennhurst (about $110 per day versus $129 per day at Pennhurst).

(4) A few people in the CLAs showed extremely high costs (two people were over $270 per day) during their first year because their behaviors demanded complete staff complements but no roommates; these two individuals showed improvements sufficient for roommates to move in and costs to drop correspondingly within the second year.

(5) The fiscal burden shifted sharply from Federal to state sources for the people who went to CLAs; because Federal ICF/MR funds were being used for Pennhurst but not for CLAs, the state contributed about $57 per day for people at Pennhurst, and about $98 per day for people in CLAs.

Consumer Interviews -- Satisfaction

In this part of the study, we have interviewed a sample of people before and after they left Pennhurst. The sample is not representative of all the people who lived at Pennhurst, the majority of whom could not respond to a verbal interview. Nevertheless, we have learned a great deal by talking to people directly, both about their own feelings, and about the methodology of conducting direct interviews with consumers.

We interviewed a sample of 56 verbal people in 1980, while they were still at Pennhurst. We included check questions for each of the important questions, so that we could eliminate contradictory and inconsistent responses from the statistics. The 56 people were generally happy and satisfied with all aspects of Pennhurst. We found that 39% reliably said they wanted to stay at Pennhurst, and only 23% reliably said they would like to go live somewhere else. (The remaining 38% of the people were inconsistent or did not answer these questions.)

Thirty of the original 56 people have now moved and have been reinterviewed in their new community homes. Their responses show that they are significantly happier than they were at Pennhurst in most aspects of their lives. Twelve of these 30 people reliably expressed happiness about living at Pennhurst in 1980; now, 22 reliably say they are happy living in the CLA. The proportion of people who reliably want to keep on living in the CLA is up to 63% (from the 39% at the institution). There has been no decrease in any area of satisfaction or happiness.

Among the other 26 people, who are still at Pennhurst awaiting placement, our 1984 reinterviews show no changes at all in satisfaction or happiness from 1980.

We have noticed a sharp increase in consistent answers from the first to the second interviews, both among movers and stayers. Having considered many possible explanations, we tend to favor the idea that these people, who had seldom been asked their opinions about important things, were at first unprepared and perhaps somewhat nervous. But the interview, which was indeed an unusual event in their lives, may have been the subject of much thought afterward. By the time of the second interview, they had actually clarified their own opinions about what they liked and how they wanted to live. This suggests that consumer input, if we will ask for it and listen to it, may become progressively more useful.

Qualities of Environments

We have found that the CLAs are considerably higher on scales of normalization and individualization than were the living areas of Pennhurst. We therefore conclude that people are better off in terms of these two environmental qualities after moving from the institution to a CLA..

In our work on measuring environmental qualities within community residences (including physical comfort, 18 aspects of normalization, individualization, life safety, encouragement of autonomy and activity, size, and staffing patterns), we have tried to shed light on what environmental qualities "make a difference" for individual growth and development. Our preliminary findings indicate that the degree of normalization of a community setting makes a difference, with people in more normalized settings making more progress. We also find evidence that size makes a difference, with people in smaller settings doing slightly better (even though the size of the settings only ranges from 1 to 8 people). The data also hint that, controlling for differences in the level of functioning of the people in the community settings, more regimentation may be associated with more growth. This tentative finding demands more investigation. In another analysis, we see a suggestion that settings with "too many" staff may produce less growth among the people living there -- but we need long and careful scrutiny of what might constitute "too many" before saying any more.

Findings of equal or greater importance have arisen from unexpected quarters. All of the programmatically oriented measures we have used are rather highly correlated with the adaptive behavior of the occupants. This means that programs serving people with more serious disabilities will automatically receive lower ratings on these measures. That is not a desirable property for any set of environmental scales or standards.

Another unexpected finding of our work is that none of the environmental scales that were available for use in this study offered adequate reliability data, not even those that were in use on a national level. Moreover, during the course of our work, we came to suspect serious reliability problems with many of the environmental instruments we used. The Pennhurst Study was not designed to do large scale reliability checks of program standards and scales, but that is certainly an area for immediate and important work.

Family Impacts

We now know from national studies that most families of people living in public institutions vigorously oppose the idea of community placement. The families of the people living at Pennhurst Center are no exception. The unique contribution of the Pennhurst study is that this is the first time families have been interviewed before and after community placement of their relatives.

We found, in 1980, that 83% of the families of people living at Pennhurst expressed satisfaction with the institution, and 72% said they were unlikely to agree with any decision to move their relatives to CLAs. We also found that opposition to the CLA idea was not related to the relative's level of retardation; moreover, families who had visited a CLA opposed them just as much as those who had not. In addition, we found that most families did not believe that their relatives were capable of learning any new skills, and we found strong evidence that many of the families had an exaggerated perception of the level of medical attention needed by their relatives.

In any case, we could comprehend the reluctance of the families to accept the CLA concept on the grounds of one fact alone: their relatives had already lived at Pennhurst Center for an average of 24 years. Change after so long is difficult for anyone.

The family of each person who went to a CLA has been reinterviewed 6 to 12 months after the move. A total of 134 families have been interviewed in this "before and after" fashion. The changes in feelings about community residential care are dramatic. Figure 3 illustrates the findings.

Insert Figure 3 Here

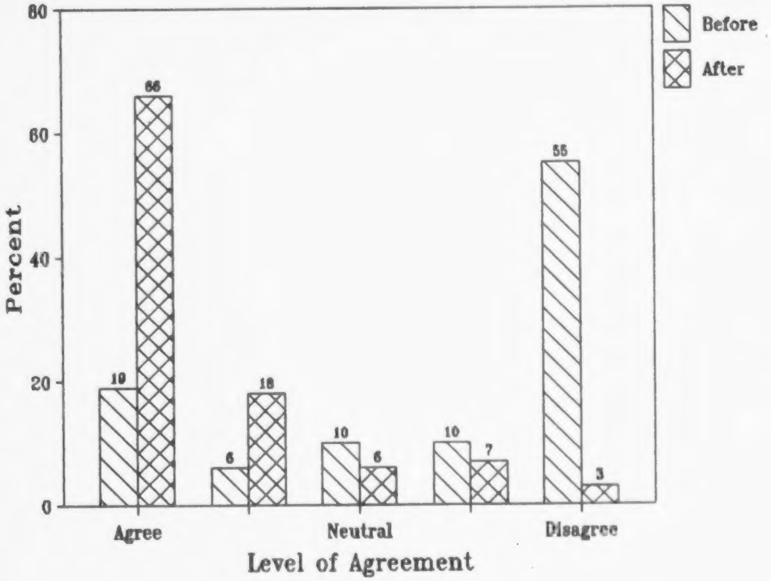
On the left side, the graph shows the increase in the proportion strongly favoring community placement, from less than 20% before to over 60% afterward. Conversely, on the right, we see that after placement, less than 5% of families strongly oppose the CLA option.

Survey results show that the families also perceive their relatives to be much happier after the move. There are significant and positive changes in practically every item on our survey.

In the areas of the relative's potential for growth and the perception of the relative's medical needs, however, the before-to-after changes are relatively small. We are

FIGURE 3

Family Agreement, Before and After



continuing to watch these attitudes in Pennsylvania to see whether they will gradually change over years of community living.

Our data also show no substantial increase in family visits after community placement. It seems that the families who visited frequently at Pennhurst continue to do so in CLAs and vice versa.

In a nutshell, we have found that initial family opposition changes drastically to surprised and enthusiastic support of the CLA option, tempered by continued concern about permanence. Our perception of the single most important finding of our work with families, other than their delight with the new mode of care, is this continued and unabated concern for permanence. Few of the families are convinced and confident that the CLA model offers a sufficient "guarantee" that their relatives will have a safe and pleasant place to live for their entire lives.

Neighbor Attitudes

The long duration of the Pennhurst Study has enabled us to investigate neighbor attitudes in a way that has not been done before: interviews with neighbors of CLAs before and after the CLAs open.

We interviewed neighbors of 8 planned CLAs about 6 months before they opened. This was before anyone in the neighborhoods knew of the planned CLA. We asked the neighbors how much they would be "bothered" if small groups of various kinds of people moved into a house in the area. The neighbors said they would be bothered very little by new neighbors with physical disabilities, or with mild mental retardation, or of a different race. They admitted that they would be bothered a lot more by people with mental illness or severe mental retardation.

The potential effect on property values was a strong concern about new neighbors with mental illness, with severe mental retardation, and of a different race. This concern was much less intense about people with mild mental retardation.

In all, it appears from our data that only about 10% to 20% of neighbors would be opposed, on their own, to a small group home for people with mental retardation, depending on the level of retardation of the people. However, this situation can probably be changed by vocal leadership, even from a small number of strong opponents.

The same neighbors were reinterviewed about 6 months after the group homes opened, and then again at about 20 months after opening. We found that only 28% of neighbors were aware that a group home had moved in at all. Among the cognizant neighbors, there was a small but significant negative shift in their general attitudes about people with mental retardation -- but this shift was visible only at 6 months after opening, and had vanished by the time of the 20 month interview. Thus we found a small and temporary negative reaction among neighbors of new group homes.

This temporary negative reaction is further documented by the fact that neighbors who knew about the group home told us that they had been much more negative about when they first heard about it than they were now.

Finally, it appears that the opposition of average citizens to imagined group homes in their neighborhoods is considerably stronger than the actual opposition among neighbors of real group homes. This presents program implementers with a fascinating double bind: if a program opens in a community, opposition will decrease, but if the opposition is strong enough, the program will never open.

Synopsis and Cautions

The 5 years of the Pennhurst Study have led to the conclusion that, on the average, the people deinstitutionalized under the Pennhurst court order are better off in every way measured. For the people who have moved from Pennhurst to small community residences, results are not mixed. They are conclusive.

Scientifically, this is not the end of the story. How do we know that deinstitutionalizations elsewhere would produce similar results? The answer is that we do not. Scientific conclusions are stated in probabilistic terms. The more a deinstitutionalization process resembles the one we have observed, the more likely it is that similar results will be seen. Any who wish to know if other efforts will obtain similar outcomes must understand the nature of the service system we have studied here, and be able to relate that to the nature of the system in their own area. To the extent that the placement process and the community service system are different, the results of deinstitutionalization may be different.

Similarly, to the extent that people in other community placement efforts are unlike the people in our study, the results of deinstitutionalization may be different from ours. Our study concerned people with very serious intellectual and other impairments. One must draw a careful distinction between the group we have studied and the people who were "deinstitutionalized" from facilities for people with mental illness (not retardation) in prior years. Some of those people were discharged with little more than a supply of medications to support them, and went on to join the ranks of the homeless who may be seen on streets and warm air vents in major cities. That was emphatically neither the kind of person nor the kind of process observed in the Pennhurst Study.

These cautions against careless generalization are important. It is also scientifically important to stress that, in the Pennhurst deinstitutionalization, the measurable improvements in the lives of the people have been very great, in order that it will be clear that such outcomes are possible.

It is also important to note that we have observed an unusual community placement process, in that 81% of the people who have moved to CLAs are labeled "severely" or "profoundly" mentally retarded. This simple fact definitively invalidates the notion that community care for people with severe or profound mental retardation cannot work.

References

Bassuk, E.L., & Gerson, S. (1978). Deinstitutionalization and mental health services. Scientific American, 238, 46-53.

Campbell, D.T. (1967). Reforms as experiments. American Psychologist, 24, 409-429.

Goffman, E. (1961). Asylums. New York: Doubleday-Anchor.

STATEMENT OF DAVID MANK, PH.D., ASSISTANT PROFESSOR, DIVISION OF SPECIAL EDUCATION AND REHABILITATION, UNIVERSITY OF OREGON, EUGENE, OR

Dr. MANK. Thank you, Senators, for the opportunity to raise about services for people with disabilities that are funded by Medicaid.

I am David Mank from the University of Oregon, and I and a number of my colleagues have been particularly concerned with employment issues related to people with severe developmental disabilities.

I have submitted the written testimony, and at this time I would just like to highlight a few major points.

It seems to me that the review of Medicaid financing of services for people with developmental disabilities provides us with an opportunity to bring in line federally funded services with the emerging policies, the values, and the research of the recent years about appropriate and integrated services. And I would like to address my comments specifically to what could be considered the most appropriate day service, and that is employment with long-term support.

Let me begin with an example. A young woman with developmental disabilities with severe mental retardation now works in her home community. She is unable to speak clearly and is considered to have very poor social skills. But a community program designed to secure employment and provide long-term support to maintain that employment located a job for this woman. With intensive training and support on the job, and in other ways, this woman now earns more than $400 a month, and lives and participates in her community in much the same way as other community members.

This woman may well need support for the rest of her life to stay in the community and to stay employed. But for most other people with severe developmental disabilities, such a possibility does not exist.

One of the reasons for that is the restrictions on the use of Medicaid funding for supporting the employment of persons with developmental disabilities.

While Medicaid funding might provide for some other kinds of services, it is difficult if not impossible for this funding to be used to support the most appropriate and desirable day service possible, and that is employment with the support to stay on the job.

The State operates under a Federal system with a major disincentive to providing this kind of employment outcome, and it is clear that the majority of Medicaid financing of services for persons with disabilities fund services in large and segregated settings. This is true even though Medicaid programs speak to promoting adaptive skills for community life. This is true even though there is a broad emerging consensus that appropriate services are community and integrated services.

This is true even though employment is highly valued in our society for all citizens. This is true even though the research and demonstrations of the recent years clearly demonstrate the desirability and the possibility of meaningful and integrated employment in regular job sites for people with severe developmental disabilities.

People receiving services funded by Medicaid have the ability and the untapped potential to work productively in our communities in integrated jobs if long-term support is available. And much of our present system of services produces few valued outcomes. Employment, with support, produces outcomes that are clear and valued.

It is time to promote appropriate services and outcomes, and provide incentives rather than providing restrictions on the use of Federal funds.

It is time to align the use of fiscal resources what is clearly possible and clearly valued. Integrated life in our communities that includes meaningful employment.

Thank you.

[The prepared written statement of Dr. Mank follows:]

SENATE COMMITTEE ON FINANCE
SUBCOMMITTEE ON HEALTH

RE: MEDICAID FINANCING OF SERVICES
FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

SEPTEMBER 19,1986

TESTIMONY SUBMITTED BY:
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Mr. Chairman, Senators:

Thank you for the opportunity to testify before the subcommittee concerning Medicaid financing of services for persons with developmental disabilities. This issue is especially important when we consider the impact of such review and decisions on the lives and quality of life of persons with the label of developmental disabilities. My purpose is to focus on issues related to day services and employment for people with developmental disabilities. There are a number of significant and positive changes happening across the country in services for people with developmental disabilities. There are also many needs and barriers to providing most appropriate, community based services and employment for people with disabilities.

I would like to offer several points for consideration to the committee related to funding of services for people with disabilities as it relates services and employment in regular community settings. Although the Medicaid funding for people with developmentally disabilities was enacted to improve state institutions, the focus, almost since the beginning has been to promote adaptive skills for community life. In fact, since 1976, specific provisions of Title XIX have promoted community life. It would seem important to keep in mind this focus as costs and outcomes are considered.

* What values should guide policy development?

There is no doubt and little discussion that enabling persons with developmental disabilities to live and work alongside the rest of us in communities is clearly preferable to life in large, segregated, isolated mini-societies and institutions. Further, it is clearly possible for their needs to be met in communities. Demonstration programs across the country show the abilities of people often found in large segregated settings. The extent to which we are successful in using public dollars to promote life in our communities is the extent to which we succeed in providing meaningful lives for people with developmental disabilities.

Persons with disabilities, advocacy groups and many others citizens assert the rights of people with disabilities are the same as the rights for all community members. This must include not only living but also working in our communities.

Strong values associated with normalized lives for persons with disabilities have emerged. At the same time there have been significant improvements in our ability to teach community and adaptive skills to persons with developmental disabilities. The last twenty-five years have witnessed notable change in the way in which we teach people with disabilities to work in community settings. What was thought impossible to accomplish two decades ago is now standard practice in many programs around the country. Research has shown the ability of people with severe and profound mental retardation to learn and perform complex work skills and earn significant wages in regular community jobs. Two decades ago, such individuals might have been found only in large, segregated settings. In addition to a substantial body of research, high quality demonstrations exist in all parts of the country that show the ability of people with disabilities and the promise of community employment.

* How are Federal dollars new spent?

While the stated focus of services for people with disabilities is community based, enormous resources continue to pay for institutional, segregated and non-normalized services. There appears to be a major contradiction in the social service system for people with developmental disabilities. On the one hand, it is both possible and desirable that people with developmental disabilities live and work in our communities. On the other hand, federal dollars continue to pay for funding of large, segregated settings which do not result in community life.

It is clear that the use of Medicaid funding for persons with developmental disabilities has increased dramatically. This is due in part to some institutional costs being shifted from state to Federal funds. It is also clear that the majority of this funding supports services that are contradictory to best practice and community living and are not based on the emerging values and the research and demonstrations of the last twenty years. Further, this contradiction is present in day and vocational services administered by State Mental Retardation Agencies. Between 1979 and 1984 there was a 179% increase in the expenditures for day services in programs administered by State Mental Retardation Agencies. Of these services, nearly 75% are segregated adult day programs with little or no access to meaningful work. Only about 3% of individuals with severe disabilities had access to integrated work in community settings. Again, this occurs at a time when there is widespread agreement that integrated work in regular community jobs is both desirable and possible.

This problem is further compounded by the number of students with developmental disabilities who are leaving high quality school programs. In Oregon alone, more that 100 students a year leave school. Nationally, it is estimated that 250,000 special education students leave school each year. Most either receive no service or are underserved in nonvocational or segregated programs.

What is clear is that the dramatic growth in costs and services are not in line with what is thought to be most appropriate and needed to meet the needs of persons with developmental disabilities. Federal funding systems for services for programs for people with developmental disabilities make available large sums of money for the maintenance of large, non-community based facilities. This creates a powerful disincentive for widespread development of community based services and community based employment. Restrictions on the use of Medicaid funds for community services create additional disincentives. On the present course, costs can be expected to increase and the development of appropriate services and employment options will be severely hampered.

* Supported Employment should be one part of future policy

There is an alternative to additional years of segregated day services for people with developmental disabilities. Supported employment provides a structure for putting people to work while providing long term support. Supported employment is working in many demonstration and pilot programs across the country with individuals with developmental disabilities many of whom were previously found in large institutions. In many communities, the only difference between one individual living and working in the community and another individual living in an institution is that one person had the chance for community service even though there may be no difference in their disabilities, support needs, IQ, or behavior. The person who remains in the institution may well be there because enough community services do not exist and the state operates under a federal system where significant dollars are available for that person if they stay in the institution.

Consider for example, an individual whose name is Vince. Vince spent fifteen years living in a large state institution. Vince has a measured IQ of about 30, does not speak clearly and has had a history of acting out behaviors and noncompliance in the institution. Through a community program, Vince was able to move into a supervised apartment and began working in a manufacturing plant. It was not changes in Vince's abilities that made this possible. The difference was that opportunity was provided and support delivered to make community life possible. It is a matter of using resources to support community life and work rather that paying for expensive and inappropriate non-integrated life.

Even though Vince is considered severely intellectual disabled, within a few months of leaving the institution, he had learned to ride the city bus to and from work and had learned a number of work tasks. He earns about $500.00 a month. In the institution, he earned no money. He has made friends at home and at work with people who do not have disabilities. He now contributes to society. But Vince is not totally independent. Rather, he receives regular and ongoing support from skilled professionals to make sure that he continues to live in the community and to work productively. His life is now much like that of working adults in any community.

The only difference between Vince and many, many other people who are still found in large, segregated settings is that Vince has the opportunity to live and work in the community. He still needs support, assistance and supervision. He may well need this support for the rest of his life. But there is no reason for Vince, nor for other individuals with developmental disabilities to remain in institutions except that too few community employment services exist across the country. This is true at the same time that people across the country have agreed on the need for and promise of supported employment. Yet significant resources continue to pay for placements in large institutions. The kind of life that Vince now has can be provided often for no more, and many times for less, than it costs to pay for an institutional placement. Individuals will require different levels of support. Some individuals will need intensive and ongoing support. Others will need less intensive support or only intermittent support to be successful in their communities.

In the recent past, initiatives have begun by the Office of Special Education and Rehabilitative Services and the Administration on Developmental Disabilities to promote supported employment. States across the country are looking for ways to make integrated and supported employment a reality in local communities. If the primary purpose of Medicaid and federal programs for services for people with developmental disabilities is to promote adaptive skills for community life, then it is critical to find ways to insure that resources go to providing what is now possible, desirable and much needed. Different incentives are needed. Disincentives must be removed. Federal scale programs and policies are needed which promote community life, promote integration and promote normal lifestyles. Integrated employment with ongoing support is one important piece of a system that makes people with disabilities a part of our communities. There is now an opportunity to align resources with stated goals and needed outcomes that promotes lives of quality with jobs in our communities for people with developmental disabilities.

Thank you.

Senator DURENBERGER. Thank you very much, Dr. Mank.

John Chafee?

Senator CHAFEE. Well thank you, Mr. Chairman. I must say, this is an extraordinary group of witnesses of great experience and talent. And I personally want to thank each of you for taking the trouble to come here. You have come from a long distance. And my questions will not necessarily be in the order of your statements.

Mr. Conroy, the Pennhurst study, of course, is the study that we refer to so often, and people will try to quarrel with it one way or another. Could you briefly describe to us what type of preparations were made before the placement—outplacement from Pennhurst was made? What process was gone through as far as preparing the individual, and making certain that the community facility met the needs?

Mr. CONROY. In this case, the judge was wise enough to order what is common sense, I think, and that is that the transition must be made gentle, and the person must be involved in the planning to the extent possible. There must be trial visits. The family must be involved. You need continuity and gentleness in the transition.

The judge also ordered that all services must be in place in the community before the person moves. That requirement made sure that there was a day program and a place to live. There was weekend staffing. The staff had already been hired. The services were in place. And I think that is only the sensible thing to do.

In addition, the judge ordered a very carefully written standardized, individually habilitation plan. That was prepared before the person moved. There was even a transitional habilitation plan.

The upshot of it is that with proper preparation, deinstitutionalization can be done correctly and with safety.

In past deinstitutionalizations, I have witnessed people dying from careless transfers from one place to another. In this case, it was done with care, and it was successful.

Senator CHAFEE. What about the continuing supervision, the assurance of the quality remaining there as you go along?

Mr. CONROY. That, of course, in my mind is one of the challenges for the future as we shift from one sort of care model to another in this country, and particularly to a decentralized one. We must assure that monitoring is intense.

Some would argue that neighbors are one level of that monitoring. I agree. When you are in regular housing stock, and abuse occurs, neighbors may participate in the solution. But there are lots of levels of monitoring. I believe fiscal monitoring at the local level is important. Case management is, in my opinion, the most important level of monitoring.

Someone has to visit every person every month, a third party, not hired by the provider agency, someone with no vested interest. Case management is intended to serve that function. And that must be supported financially.

Finally, the kind of monitoring that our outfit does is quantitative. We visit every person every year. We survey every family every year and we measure, to the extent we know how to measure, the qualities of the places where they are living and working.

That is quantitative and it is done once a year. And we are able to raise red flags. When we find a person in trouble, we notify the appropriate State agency, and in our system, luckily, action is taken.

Senator Chafee. Dr. Braddock, under the way the ICF/MR works, if you have—if the State has a small facility that is so constructed that it meets the requirement, then they get the reimbursement. But if the facility does not meet—if you just take a regular home, it is my understanding, just buy a home, and do not widen the corridors, and do all sorts of frequently extremely expensive steps, then it doesn't qualify. Am I correct in that?

Dr. Braddock. That is a correct interpretation.

Senator Chafee. And what would be your recommendation in connection with this? What do you think we ought to do?

Dr. Braddock. I think you touched on the fundamental problem in your opening remarks, Senator. The problem is the medicalization of the program. I don't think we will resolve problems like this probably until we perhaps even go so far as to extricate the resources for DD people out of the ICF/MR Program, and perhaps set up a separate agency to deal with it, and organize regulations in such a way that they are congruent with modern day principles of normalization and least restrictive environment.

I would point out that at the Federal level in mental illness we have the National Institute of Mental Health to guide the Nation's Mental Health Program. We have no counterpart in developmental disabilities. It is unfair to compare the $50 million budget of the administration on developmental disabilities and its organizational clout with that of the National Institute of Mental Health.

I think we need an agency at the highest levels of Government in Washington, and we need single State agencies in the States—freestanding agencies that can champion the rights and interests of DD people and help us get regulations that prevent foolish kinds of stipulations like you have just described from occurring.

Senator Chafee. I suspect, but I am not sure, to qualify for the ICF/MR you have to have a facility that two wheelchairs can pass in the corridors even though the residents may not be in wheelchairs.

Dr. Mank, what kind of jobs can these individuals that you described—and they seem to be fairly severely retarded in your description—what type of jobs are they? What do the problems say with the minimum wage? These are workshops of some type?

Dr. Mank. No; integrated community jobs, Senator. I know of individuals with severe developmental disabilities that are in a number of different kinds of jobs, from manufacturing to service occupations.

Under emerging programs of supported employment, some individuals will be paid in excess of the minimum wage according to their productivity and their efforts. But other individuals who may work more slowly need not be excluded from integrated community employment on the basis of productivity.

It is possible to acquire Department of Labor certificates to pay based on productivity even in community jobs rather than in segregated settings.

Senator Chafee. Dr. Lakin, we appreciate your testimony and the thoughts you had. Here is a question I would like to ask the panel as a whole, any one of you. The thrust of this program, the community living amendments, was not to get it cheaper. That was a fringe benefit. If it is there, if it will reduce costs, fine. But the thrust of it is way beyond that. However, in your Pennhurst study, Mr. Conroy, you indicated that the costs were lower, but then you said that the costs were lower because the cost of the employees was lower. I don't quite understand. Why does it work out that way? Why is the cost to the employees lower?

Mr. **Conroy**. The employees at Pennhurst, Senator, were State employees and they were represented by unions. And at the time of our first fiscal analysis, the average direct care worker was earning a little over $14,000 a year with a benefits package of just over 40 percent. The private providers in the community service system hired people who were not represented by a union. They were entry level paraprofessionals, if you will, and they were earning an average of $9,600 a year with a 21-percent benefits package. And that is the difference in the cost between the two programs.

That is something that, of course, cannot continue for a very long time in this country. It is certainly not fair. And the difficulty of the work is quite similar.

Senator **Chafee**. Have you got any thoughts on that, Dr. Lakin?

Dr. **Lakin**. Well, it is just important to realize that personnel costs are the major costs of any kind of residential care. And that if those costs are equated, we really should not expect great differences in providing for people with similar characteristics. It is just not going to happen.

So it has got to be more than cost. You are right. It has got to be commitment. We have to decide it is right to do it and act from that, and not some expectation of savings over the long run.

Senator **Chafee**. Well, I want to make that very clear, that is not the thrust of the program, the savings. It is just that the subject is raised on occasion. Oh, there is going to be more cost or this is less costly. I just want to know your thoughts.

You suggested something like a reimbursement system similar to the DRG. I am not quite sure how that would work.

Dr. **Lakin**. Well, I am not quite sure how it would work either, but I am scared to death that a committee like this is going to continue to ignore what it ought to be doing for fear of some unknown population out there that isn't presently receiving services that may show up if services presently available only in institutional settings are made available in alternative forms: habilitation programs in the community, support the families, and so forth.

My feeling is that if we need to deal with that, we ought to deal with it by limiting the cost per beneficiary and making sure that the services are increased. I am just convinced that what you are about should not be hindered by an overall concern about cost. We need to deal with that cost with limits, if necessary, so we can get on with what you have rightly recognized as the duty of this Congress.

Senator **Chafee**. Well, thank you all very much. I appreciate each of you coming. And I may have written questions for you subsequently and I would appreciate it if you would answer them. Thank you.

Senator **Durenberger**. I think we will too. And we appreciate the testimony of each of the witnesses.

Our next panel will be Barbara Matula, chair of the Committee on Long-Term Care, State Medicaid Directors' Association of the American Public Welfare Association, from North Carolina; Urbano Censori, deputy director of the Bureau of Community Residential Services, Program Development Policy and Standards, Department of Mental Health, State of Michigan. I would like to see your card. Also representing the National Association of State Mental Retardation Program Directors, James Towes, assistant administrator, Oregon Developmental Disabilities Program Office; and Dr. Edward Skarnulis, the director of mental retardation division of the Department for Human Resources, State of Minnesota.

Let's begin in the order of introduction. And, again, you have all been here, heard the rules, and you have also noticed how well all your predecessors at the witness table have adhered to the so-called 5-minute rule and we appreciate that. And the people that come after you in particular will appreciate that.

We will begin with Barbara.

STATEMENT OF BARBARA D. MATULA, CHAIR, COMMITTEE ON LONG-TERM CARE, STATE MEDICAID DIRECTORS' ASSOCIATION, AMERICAN PUBLIC WELFARE ASSOCIATION, RALEIGH, NC

Ms. **Matula**. Thank you very much.

I am not going to bother reading over my testimony for you. I know that you are familiar with it. But there are some points that I think are important for us to make in the Medicaid Program, some as they relate to cost, and, more importantly, some as they relate to the waivers that we have been talking about.

The quality of care in ICF/MR's has gone up as has the cost, but we believe the costs have stabilized now. Still, we are putting as much as $40,000 a year into institutional care when the ICF/MR waiver cost in my State, delivering a wide package of care, including respite, ranged from $12,000 to $19,000 per year.

When we talk about making it easier for us to get waivers, we might keep in mind that the number of people we can serve in our waiver program is tied to the number of ICF/MR beds. And it is conceivable that if we could close institutions we would lose the slots to serve the people in the community. Ironic but true.

Senator **Chafee**. You mean because you would not have the facilities in the community?

Ms. **Matula**. That is right. We could not, under the waiver, serve the people in the community if we closed the institutions.

We also have for the children who are in institutions now, clearly, an eligibility bias, in that their parents' income is not counted toward their care in the institution. But if that child is cared for in his home, their income is counted and they probably will not qualify for Medicaid. As you know, those guidelines are well below poverty.

So when we talk about the waivers and making them easier, we need to institutionalize some of those biases in the home and community based program as well.

I suppose the size of institution is an issue that you will be dealing with. I think that we are seeing that as some of our small-bed facilities in North Carolina move to take the more profoundly retarded and the multiply handicapped, they are losing some of the economies of scale in delivering the extensive services that the larger institutions have. So if cost is not an issue to you, I would project that as we move the more severely retarded into the smaller institutions, we can expect the cost to easily be as great as large State institutions, regardless of the salary differential, if not higher.

I think that the waiver program has gone a long way toward realizing some of our goals, but I would sum up my comments by saying that the participation still is somewhat lopsided: 300 people in North Carolina in the waiver program; 3,000 in the ICF/MR. I would not say that any Medicaid director would tell you that we have no need for ICF/MR's. I believe we do. But I do think that the imbalance is clear and it is one that is dictated by the formula in the waiver.

Thank you.

Senator **Durenberger**. Barbara, thank you. And you are a frequent visitor to this subcommittee, and we always appreciate the insight that you have, not just only individually—that is appreciated—but the sensitivity to what the other 49 of your counterparts are doing in the rest of the country.

[The prepared written statement of Ms. Matula follows:]

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FOR THE
COMMITTEE ON FINANCE
U.S. SENATE

HEARINGS ON INTERMEDIATE CARE FACILITIES
FOR THE
MENTALLY RETARDED (ICF/MRs)

SEPTEMBER 19, 1986

Mr. Chairman, members of the committee, good morning. I am Barbara D. Matula, director of the North Carolina Division of Medical Assistance and current chair of the Long-Term Care Committee of the State Medicaid Directors' Association of the American Public welfare Association.

I come before you today to present the views of state Medicaid directors regarding the financing of intermediate care facilities for the mentally retarded (ICF/MRs). In addition, I will discuss the state Medicaid director's views on appropriate care for the mentally retarded and developmentally disabled. The state Medicaid directors want to provide the committee with the most complete perspective on these issues, and we hope our input will be of value. The Medicaid program funds a large part of the care for the mentally retarded and developmentally disabled in this country, and because this funding is directed towards institutional care our program is at the center of the more general debate over whether institutional care or care and services provided in the home and the community is more appropriate for those in need of long-term care.

This morning in discussing financial issues regarding ICF/MRs I will give some background on: (1) the large costs increases in this area of the Medicaid budget; (2) why they have occurred; and (3) show that these costs have come under control in recent years. I will conclude my remarks on finances by discussing the issue of educational versus habilitative services which has been a controversy for the past few years. In the latter part of my testimony, I will talk about the appropriate care setting for mentally retarded and developmentally disabled individuals, emphasizing the states' need for latitude in administering these programs.

In 1985 approximately $4 billion in federal and state funds were spent on the services provided by ICF/MRs under the Medicaid program. ICF/MR payments constituted 12 percent of the entire program in 1985. Over the past several years the growth in the cost of ICF/MRs has been of particular concern to state Medicaid agencies and decision makers in washington. while the ICF/MR costs in Medicaid increased at a rapid rate in the late 1970s and early 1980s, they have now begun to decline as a portion of overall program costs. In FY 75 ICF/MR costs constituted 2.8 percent of Medicaid costs. In FY 80 they were at 11.1 percent and hit a peak of 13.5 percent of Medicaid expenditures in FY 83. So a leveling off has occurred for ICF/MRs cost, relative to other Medicaid costs, and have maintained a level of 12 percent in FY 85. ICF/MR service expenditures are now growing at approximately the same rate as the rest of the Medicaid program.

It is important to understand that the earlier rapid growth was not due to frivolous spending on the part of states, as some have suggested. Two related factors have contributed to the rapid increase in Medicaid costs for ICF/MRs. First, States have shifted the care of persons from state-only financed programs into the Medicaid program since ICF/MRs services were first covered by Medicaid statute in the early 1970s. Second, the overall quality of care provided to these individuals has improved, resulting in increased costs.

Neither of these changes is surprising. Individuals receiving ICF/MR service under Medicaid numbered 55,000 in FY 75, 125,300 in FY 80, and 155,200 in FY 83. Some of the ICF/MR facilities are state owned, but over

TIME CORPORATIONS HAVE BUILT FACILITIES ACROSS THE COUNTRY AND ENCOURAGED THE ADMISSION OF PERSONS WHO WERE NEVER BEFORE ON MEDICAID. THE INTENT OF THE STATUTE, PROVIDING FUNDING FOR ICF/MR SERVICES UNDER MEDICAID, WAS TO IMPROVE THE QUALITY OF CARE TO THE MENTALLY RETARDED AND DEVELOPMENTAL DISABLED. THE NEW FUNDING WAS TIED TO FEDERAL REQUIREMENTS WHICH SPELLED OUT THE QUALITY OF CARE TO BE PROVIDED. IN ACCEPTING THESE FEDERAL FUNDS, STATES HAVE ACCEPTED THE CHALLENGE OF PROVIDING HIGH QUALITY CARE IN ICF/MRS AS OUTLINED BY THE FEDERAL STANDARDS. ACCOMPLISHING THIS GOAL CARRIES A HIGH COST. MEETING FEDERAL STANDARDS MEANS SPENDING UPWARDS OF $40,000 A YEAR ON AN INDIVIDUAL IN AN ICF/MR. SO WHEN ACCOUNTING FOR THE HIGH COST OF ICF/MRS PAYMENTS UNDER MEDICAID, IT IS NECESSARY TO CONSIDER THE QUALITY OF CARE BEING PROVIDED. THE TWO CANNOT BE SEPARATED.

AS I HAVE ALREADY POINTED OUT, THE PERIOD OF A RAPID INCREASE IN COSTS FOR ICF/MR SERVICES HAS SLOWED DOWN, SIGNALING AN ACCOMPLISHMENT OF EARLIER GOALS TO PROVIDE A HIGH QUALITY OF CARE TO INDIVIDUALS IN ICF/MRS. THE STATES BELIEVE THAT MANY OF THE FINANCING CONCERNS OF THE PAST ARE NO LONGER A PROBLEM. WE MUST CONTINUE TO WATCH THESE EXPENDITURES TO AVOID UNNECESSARY INCREASES, BUT THE SITUATION HAS CHANGED SIGNIFICANTLY.

THE ISSUE OF DEFINING EDUCATION AND VOCATIONAL SERVICES ALSO NEEDS TO BE CONSIDERED. AS YOU KNOW, BEGINNING IN 1984, THE OFFICE OF THE INSPECTOR GENERAL OF HEALTH AND HUMAN SERVICES, BEGAN REPORTING THAT FEDERAL MEDICAID FUNDS WERE BEING SPENT FOR EDUCATIONAL AND VOCATIONAL SERVICES; THAT THESE SERVICES SHOULD HAVE BEEN FUNDED UNDER THE APPROPRIATE FEDERAL PROGRAMS FOR SUCH SERVICES RATHER THAN BY MEDICAID, A PROGRAM FOR PROVIDING HEALTH CARE. WHILE THE STATE MEDICAID AGENCIES DID NOT AGREE WITH ALL OF THE IG RULINGS, THEY CERTAINLY BROUGHT ONE IMPORTANT ISSUE TO LIGHT. THE MEDICAID PROGRAM DID NOT HAVE A GOOD DEFINITION OF WHAT CONSTITUTED AN EDUCATIONAL SERVICE VERSUS A HABILITATIVE SERVICE. STATE MEDICAID AGENCIES ARE NOT INTERESTED IN PAYING FOR SERVICES THAT ARE MORE APPROPRIATELY COVERED BY ANOTHER PROGRAM.

I AM PLEASED TO SAY THAT OVER THE PAST YEAR A WORK GROUP OF STATE MEDICAID DIRECTORS AND THE HEALTH CARE FINANCING ADMINISTRATION (HCFA) OFFICIALS HAVE BEEN MEETING TO ESTABLISH CLEAR DEFINITIONS OF EDUCATIONAL AND VOCATIONAL SERVICES, AS DISTINCT FROM SERVICES COVERED BY MEDICAID, BASED ON FEDERAL STATUTE AND THE STATE OF THE ART IN TREATMENT FOR THE MENTALLY RETARDED AND DEVELOPMENTALLY DISABLED. IT HAS BEEN ONE OF THE MORE COLLEGIAL AND, COOPERATIVE EXPERIENCES FOR THE STATE MEDICAID AGENCIES IN RECENT YEARS AND WE APPLAUD HCFAS LEADERSHIP AND OPENESS THROUGHOUT THIS PROCESS.

I WOULD LIKE TO TURN YOUR ATTENTION NOW TO QUESTIONS OF APPROPRIATE CARE FOR THE MENTALLY RETARDED AND DEVELOPMENTALLY DISABLED. IT HAS LONG BEEN THE STATE MEDICAID AGENCIES' POSITION THAT STATES MUST BE GIVEN LATITUDE IN ADMINISTERING OUR PROGRAMS. AS YOU KNOW THE MEDICAID PROGRAM, ORIGINALLY DESIGNED AS A HEALTH CARE PROGRAM, HAS STRONG BIASES TOWARDS PROVIDING CARE IN INSTITUTIONS RATHER THAN IN THE COMMUNITY, WITHIN THE CONTEXT OF A HEALTH MODEL OF CARE RATHER THAN A SOCIAL SERVICES MODEL. THIS BIAS EXISTS IN BOTH THE ELIGIBILITY REQUIREMENTS AND FINANCIAL INCENTIVES OF THE PROGRAM. DESPITE THESE BIASES STATES HAVE PUSHED FOR DEINSTITUTIONALIZATION AND SIGNIFICANT STRIDES HAVE BEEN MADE OVER THE LAST DECADE.

WITHIN THE MEDICAID PROGRAM STATES HAVE SOUGHT WAYS TO PAY FOR ALTERNATIVES

TO INSTITUTIONAL CARE. THE MOST NOTEWORTHY OF COURSE IS THE HOME AND COMMUNITY-BASED SERVICES WAIVER PROGRAM ESTABLISHED BY CONGRESS IN 1981. CURRENTLY 35 STATES HAVE 44 ACTIVE WAIVERS TO PROVIDE CARE TO MENTALLY RETARDED AND DEVELOPMENTALLY DISABLED INDIVIDUALS IN THE COMMUNITY. THIS IS NEARLY HALF OF THE 104 ACTIVE WAIVERS THROUGHOUT THE COUNTRY. HOWEVER, THIS AVENUE FOR PROVIDING APPROPRIATE CARE HAS TO DATE BEEN A MUCH NARROWER ONE THAN THE STATES EXPECTED. WE HOPE THAT THIS SITUATION WILL IMPROVE AS A RESULT OF THE ACTIONS OF THIS COMMITTEE LAST YEAR, AND CONGRESS AS A WHOLE, TO AMEND THE HOME AND COMMUNITY-BASED WAIVER PROGRAM.

THE STATE MEDICAID AGENCIES BELIEVE THAT ULTIMATELY, IF WE ARE TO PROVIDE ALTERNATIVE CARE IN AN APPROPRIATE SETTING TO ALL OF THOSE IN NEED OF LONG-TERM CARE, HOME AND COMMUNITY-BASED CARE SERVICES MUST BE AN OPTION UNDER STATE MEDICAID PLANS. WITHOUT SUCH FLEXIBILITY WE WILL NOT BE ABLE TO PROVIDE THE APPROPRIATE CARE THESE INDIVIDUALS NEED. THE ARGUMENT AGAINST SUCH A CHANGE IS THAT IT WILL LEAD TO SIGNIFICANTLY HIGHER COSTS, BRINGING ON ANOTHER CYCLE OF PROGRAM INFLATION. THE STATES BELIEVE THAT WE CAN CONTROL SUCH POTENTIAL COSTS THROUGH EFFECTIVE CASE/MANAGEMENT AND OVERSIGHT.

I ALSO WANT TO EMPHASIZE THAT IT IS NOT THE STATE MEDICAID AGENCIES' POSITION THAT THE ONLY APPROPRIATE SETTING TO PROVIDE CARE TO THE MENTALLY RETARDED AND DEVELOPMENTALLY DISABLED IS IN THE COMMUNITY AND NOT IN ICF/MRS. WE BELIEVE THAT BOTH OPTIONS MUST BE AVAILABLE WITH THE DECISION ON WHICH SETTING IS MOST APPROPRIATE BEING MADE BY THE INDIVIDUAL'S FAMILY, COMMUNITY PROFESSIONALS, AND STATE ADMINISTRATORS. WE DO NOT BELIEVE THAT COMMUNITY CARE IS THE ONLY CORRECT SETTING FOR ALL INDIVIDUALS. WE CANNOT

SUPPORT THOSE WHO BELIEVE THAT SEVERELY AND PROFOUNDLY MULTIPLE HANDICAPPED INDIVIDUALS REQUIRING OPTIMAL MEDICAL AND NURSING CARE SHOULD BE HOUSED IN 8 BED UNITS IN THE COMMUNITY. THIS IS NOT ECONOMICALLY SOUND NOR IN THE INTEREST OF THOSE NEEDING A HIGH LEVEL OF CARE. THE DECISION NEEDS TO BE EVALUATED OBJECTIVELY IN EACH CASE. BUT HAVING MEDICAID FUNDING AVAILABLE FOR COMMUNITY OPTIONS IS CRITICAL TO THE SUCCESS OF SUCH A SYSTEM.

THANK YOU FOR INVITING ME TO PRESENT THE STATE MEDICAID AGENCIES PERSPECTIVE ON THESE ISSUES. I WOULD BE HAPPY TO ANSWER ANY QUESTIONS YOU MIGHT HAVE AT THIS TIME.

Senator **Durenberger**. Mr. Censoni.

STATEMENT OF BEN CENSONI, DEPUTY DIRECTOR, BUREAU OF COMMUNITY RESIDENTIAL SERVICES, PROGRAM DEVELOPMENT POLICY AND STANDARDS, DEPARTMENT OF MENTAL HEALTH, STATE OF MICHIGAN, LANSING, MI; AND CHAIRMAN, GOVERNMENTAL AFFAIRS COMMITTEE, NATIONAL ASSOCIATION OF STATE MENTAL RETARDATION PROGRAM DIRECTORS, INC.

Mr. **Censoni**. Thank you, Mr. Chairman.

With the dialog that you had with the administration, which some was found interesting and frustrating and funny at times, and what is going on here, all I really have left to say is thank you for having me today, and I will answer any questions that you may have.

But there were three or four themes I think that have come out of the testimony that we probably should keep in mind. And really they are the themes that ultimately, if we don't take care of, we won't really have true Medicaid reform when it comes to serving the people with developmental disabilities.

And the one that has clearly been stated so far a number of times, and will be later, is the notion that there is an institutional bias. But as a person in a State who works with this program day in and day out from the provider end, if you would, it is ultimately clear to me and to my colleagues—and, in fact, that bias does exist and it is pervasive—it is still a lot easier for me to institutionalize a child at $300, $400 a day than it is to get that kid back home with some support with his own family. That is a very difficult thing to do in terms of Medicaid funding.

There is a clear disincentive to move to the community because those things that are institutionalized by their very nature are also the safest forms of funding. So that when States go from an ICF/MR from our base, for example, to a waiver base, one of the things that they are doing is they are taking a rather secure—you know, 12, 13 years it comes in like clockwork—set of funding parameters, and moving into a community into the community system like a home and community-based waiver, where there is no guarantee, especially with the elaborance of formulas and requirements and other things that you have to meet. There is very little in those waivers related to client services and quality. There is a lot about cost and balance in terms of numbers, et cetera.

The system is definitely geared toward dependency building. There is no question about that. And, again, you have heard that. But if we don't deal with that issue somehow, you cannot really have Medicaid reform for developmentally unstable people because, in fact, to illustrate Dr. Mank's testimony, we have in our State 8,000 people in something that is called clinic services, and as long as we keep those people in clinic services, which is really sort of health-related daytime activity kind of thing with transportation, we are relatively assured of receiving Medicaid funding. Now that is a highly dependency building model; there is no question about it.

If we wanted to move those people into something that would create less dependency or help people become independent, like supported employment, we would immediately lose funding for them.

So the dependency buildup, the dependency bias in Medicaid is very clear.

Another problem that I don't think has been talked about, but it comes out with some of the discussions around look behinds and some other things, is this notion of all inclusive services that is built into most of the Medicaid systems for persons with disabilities. In effect, what it says is, here are the parameters, and you get these services whether you need them or not. I mean, any rational person, for example, would not provide ongoing physical therapy evaluation every 3 months, 6 months, or annually for a person who does not need them. We don't dare not do that because on our next look behind we may have some problems with whether we are providing active treatment and we may get discertified.

So we have got to do something about making sure that people absolutely get what they need, but also making sure that we don't force upon them all kinds of procedures and other intrusive things that they really do not require. And that is part of the cost problem that everybody is talking about.

Now there is a way to solve this problem, but I do not have time because my yellow light just went on. And it is already in the system, in effect. There is something called the State Plan Amendment that most of Medicaid operates under. And we believe that if we went to a State plan amendment process instead of all this waiver and a little bit here and a little bit there, and just sort of this elaborance of small pieces, we could go back to the basic.

Medicaid is a program that was intended to be a cooperative program between the Federal Government and State government. We both share in the cost. There are agreements about what services get provided, but the State plan amendment process does not have all these other things built in, does not require all these other things to occur that you are hearing so much complaint about. And we think, especially if we could build in some incentives toward community, and some disincentives toward staying in institutions, that that process would work quite well. And that system has been in place since the beginning of Medicaid.

Thank you.

Senator DURENBERGER. Thank you very much. Mr. Toews.

[The prepared written statement of Mr. Censoni follows:]

STATEMENT OF TESTIMONY

on

Medicaid Financing of Services for Persons With Developmental Disabilities

Respectfully Submitted

to the

Subcommittee on Health

of the

SENATE FINANCE COMMITTEE

The Honorable David Durenberger, Chairman

by

Ben Censoni

Director, Community Residential Services
Michigan Department of Mental Health

speaking on behalf of

National Association of State Mental Retardation
Program Directors, Inc.

September 19, 1986

I. INTRODUCTION

My name is Ben Censoni. I am the Director of Community Residential Services within the Michigan Department of Mental Health. In that capacity, I am responsible for overseeing the Department's efforts to design and implement community-based services for persons with mental illness and developmental disabilities across the State. I also serve as Chairman of the Governmental Affairs Committee of the National Association of State Mental Retardation Program Directors (NASMRPD). Today, I appear before the Committee as a representative of the Association, although in my testimony I will draw extensively on my experiences in Michigan.

The membership of NASMRPD consists of the designated officials in the fifty states and territories who are directly responsible for the provision of institutional and community services to a total of over half a million developmentally disabled children and adults. According to statistics compiled by the University of Illinois at Chicago, federal Medicaid payments on behalf of an estimated 150,000 residents in intermediate care facilities for the mentally retarded (ICF/MR) totalled $2.6 billion in FY 1985. Of this total, an estimated $1.9 billion was expended in large public and private institutions, while the remaining $700 million was obligated for community-based residential services.[1] An additional $930 million was claimed by the states for non-institutional services on behalf of Title XIX-eligible clients with mental retardation or developmental disabilities during FY 1985, including reimbursement for acute care and various outpatient services.[2] Furthermore, according to the Health Care Financing Administration (HCFA), as of September 30, 1985, over 22,000 recipients with developmental disabilities were participating in programs financed through Medicaid home and community care waivers.[3]

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[1] Braddock, David, Richard Hemp and Ruth Howes, Public Expenditures for Mental Retardation and Developmental Disabilities in the United States: Analytical Summary. Monograph No. 6, Public Policy Monograph Series, Institute for the Study of Developmental Disabilities, University of Illinois at Chicago, March, 1985, p. A-7.

[2] Braddock, David, Federal Spending for Mental Retardation and Developmental Disabilities, Monograph No. 7, Public Policy Monograph Series, Institute for the Study of Developmental Disabilities, University of Illinois at Chicago, July, 1985, p. 78.

[3] Personal communication with Brian Burwell, Systemetrics, Inc., September 3, 1986.

Federal Medicaid payments constituted over a third of the aggregate revenues received by state MR/DD agencies in FY 1984 -- up from 19.3 percent in FY 1977.[4] It should be obvious from these figures that our Association has a vital stake in federal Medicaid policy.

II. MAJOR TRENDS IN PROGRAMMING FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

Over the past ten years, we have witnessed a historic shift in the states' approach to serving persons with developmental disabilities. persons. Instead of incarcerating such individuals in large, remote, custodial institutions, the states have begun to provide a wide array of community-based day and residential programs for them. It is not unusual today to find persons who had been in institutions for twenty years or more living and working independently, or to see children who in past years would have been placed in institutions enjoying life with their biological, adoptive or foster families.

This dramatic shift is reflected in both the decline in the number of persons served in large, state-operated institutions (from 166,247 in 1974 to 109,827 in 1984) and in the evolving patterns of state expenditures. For example, a recent analysis completed by the University of Illinois at Chicago revealed that, between FY 1977 and FY 1984, total state expenditures on behalf of developmentally disabled persons in community settings increased from $745 million to $3.1 billion, or by 316 percent. Of equal importance, this trend was evident in almost all states. In fact, 44 of the 51 jurisdictions studied experienced a real, after inflation growth in community outlays over the eight-year period.[5]

In FY 1984 appropriations for community services constituted 41 percent of the total amount budgeted for MR/DD services by the fifty states (i.e., excluding education and vocational rehabilitation), compared to 23 percent in FY 1977. Furthermore, in 1984 eleven state MR/DD agencies spent more than half of their annual budgets on community-based services -- up from two in 1977.[6]

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[4] Braddock, et al., Public Expenditures..., Ibid., p. A-7

[5] Braddock, David, Richard Hemp, Ruth Howes, Financing Community Services in the United States: An Analysis of Trends, Monograph No. 13, Public Policy Monograph Series, Institute for the Study of Developmental Disabilities, University of Illinois at Chicago, May, 1985.

Meanwhile, despite the rapid increase in federal ICF/MR expenditures (from $571 million to almost $1.9 billion), total federal-state support for institutional services plateaued over this same period, when measured in non-inflated dollars.[7] Per capita costs of institutional care, however, have risen dramatically (from $44.64 in 1977 to $106.43 in 1984).[8] This reality, combined with the effects of current Medicaid policies, is placing many states in the position of having to choose between further expansion in community-based services or costly improvements in their existing institutional facilities.

Among the other notable trends in policies governing state-local services for persons with developmental disabilities are:

1. The expanded availability of special education services. The greatly enhanced access to services for school-aged handicapped children through the local public schools has had a far-reaching impact on the role of state MR/DD agencies. Since the passage of the Education for All Handicapped Children's Act of 1975 (P.L. 94-142) and mandatory state special education statutes, the number of children served by state MR/DD agencies has dwindled rapidly. As a result, day programs now focus predominantly on post-school aged and, in some states, pre-school aged clients. This shift toward adult services has been accentuated by the population bulge associated with the "baby boom" generation and the case finding impact of expanded special education services. As a consequence, most state MR/DD agencies currently face a growing backlog of unmet demand for community-based services (both daytime and residential) among young adults who have "aged out" of special education system; at the same time, pressure to create community alternatives for current institutional residents continues to mount. Public policy increasingly is trapped between these competing demands.

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[6] Braddock, et al., Public Expenditures..., p. A-11.

[7] Braddock, David and Richard Hemp, Intergovernmental Spending for Mental Retardation in the United States: An Analysis of Trends, Monograph No. 16, Public Policy Monograph Series, Institute for the Study of Developmental Disabilities, University of Illinois at Chicago, 1985.

[8] Braddock, David, Richard Hemp, Ruth Howes, Public Expenditures..., Ibid., p. 15-17.

2. Improvements in early intervention services. Using a variety of federal, state and local funding sources, many states have begun to patch together a network of early intervention services for developmentally delayed and other handicapped infants and preschool-aged children. Twenty-one states and the District of Columbia now have laws mandating special education and related services for children beginning at age 3 or before, while 29 states use a minimum age of 4 to 6.[9] Earlier this year, the Senate passed a bill (S. 2294) which would amend P.L. 94-142 by: (a) requiring all states to lower the threshold for mandatory special education services to at least age three; and (b) establishing a new federal formula grant program to stimulate the expansion of early intervention services for handicapped infants, ages 0-2.

   Despite the progress that has been made in recent years and the growing body of scientific evidence documenting the cost-effectiveness of early intervention services, few states have a comprehensive, fully integrated system of early identification and intervention on behalf of handicapped infants and pre-schoolers. Too often the consequence of this short-sighted public policy is that children go unidentified only to be channelled later into costly lifetime care systems. The tragedy is that permanent physical and mental handicaps frequently could have been avoided or significantly ameliorated if prompt, state-of-the-art services had been available early in the child's life.

3. Expanded work opportunities for moderately to severely disabled adults in integrated employment settings. Many states have begun to place a growing number of adults with developmental disabilities, once thought to lack the capacity to engage in gainful employment, into integrated work settings. While these individuals frequently require specialized training and ongoing support, experience shows that they can be productive workers, provided they received the needed training and continuing supportive services. This shift in emphasis from care-oriented to work-oriented services has profound implications for the future configuration and cost of programming for adults with developmental disabilities, nationwide.

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[9] Report of the Senate Labor and Human Resources Committee on the "Education of the Handicapped Amendments of 1986", S. Rept. No. 99-315, 2nd Session, 99th Congress, dated June 2, 1986.

III. THE EFFECTS OF MEDICAID FINANCING ON THE DELIVERY OF SERVICES TO PERSONS WITH DEVELOPMENTAL DISABILITIES

There is no doubt that the availability of federal Medicaid reimbursements has been an absolutely critical factor in improving state-local MR/DD services over the past decade. As Braddock and others have point out, the sharp increase in federal ICF/MR reimbursements that occurred between 1972 and 1982 was a primary factor in the overall growth of state MR/DD budgets during this period. Access to such funds not only permitted the states to improve the physical environment and staffing of existing state residential centers, but it also permitted the states to expand community-based alternatives more rapidly than otherwise would have been possible.

In addition, the promulgation of federal ICF/MR standards, combined with the real or implied threat of losing federal support, has forced state policymakers to upgrade the quality of services in public and private residential facilities for persons with mental retardation. While, as the recent round of federal validation surveys revealed, deficiencies still exist in some facilities, nonetheless significant improvements have occurred in most ICF/MR facilities over the past ten years.

Despite the central role Title XIX funding has played in improving the accessibility and quality of state/local services for persons with developmental disabilities, current federal Medicaid policy inhibits, in several significant ways, the development of a more rational state-local system for serving clients with developmental disabilities. Let me briefly outline a few of these impediments.

First, existing law provides the states with powerful incentives to place and maintain persons with severe disabilities in large, multi-purpose long term care institutions, since the authority to cover various types of community-based services remains ambiguous. Historically, Medicaid support for long term care services has been confined largely to care furnished to eligible recipients in certified nursing homes. Coverage of ICF/MR services was originally designed to extend such coverage to eligible individuals with mental retardation residing in certified public institutions. While subsequently a number of states began to certify small community residences as ICF/MR providers in order to meet community placement goals, the basic precepts of the program -- i.e., a facility-based program in which recipients are to receive 24-hour care, supervision and services -- remained unchanged.

In 1981, Congress took a potentially important step toward reducing this so-called "institutional bias" of Medicaid long term care policy by authorizing the home and community care waiver program (Section 2176, P.L. 97-35). However, because the Administration has elected to impose more stringent restricitons on eligibility than required by the statute[10], the full potential of the Section 2176 waiver authority has never been realized. Congress included in the FY 1986 reconciliation act (P.L. 99-272) several amendments designed to correct the most obvious administrative excesses of HCFA and OMB, but did not address the underlying problem -- i.e., the lack of a reliable, ongoing statutory authority to cover non-institutional long term care services under state Medicaid plans.

Recognizing the inherent instability of services financed under HCFA/HHS-approved waivers, a few states have been claiming federal Medicaid reimbursement for various elements of non-institutional LTC services under existing or new state plan amendments (e.g., personal care, home health, clinic and rehabilitation services). HCFA generally has discouraged this practice, ostensibly because such services are not medical or remedial in nature but, in reality, as a means of containing growth in program coverage.

Thus, while the Administration voices rhetorical support for expanding community living opportunities to more citizens with developmental disabilities[11], current federal policies governing Medicaid -- the predominant source of federal aid for MR/DD services -- tend to impede the accomplishment of this goal. Therefore, any attempt by Congress, to rectify existing problems surrounding the utilization of Title XIX on behalf of citizens with developmental disabilities must begin with the establishment of a firmer statutory base for supporting non-institutional long term care services under state Medicaid plans.

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[10] See NASMRPD's September 13, 1985 testimony on the "Deficit Reduction Amendments of 1985", before the Senate Finance Committee, for a full explanation of the regulatory/administrative restrictions the Administration has imposed on waiver coverage.

[11] See, for example, HHS Secretary Otis Bowen's January, 1986 report to Congress, entitled, Policies for Improving Services for Mentally Retarded and Other Developmentally Disabled Persons Served Under Title XIX of the Social Security Act.

Second, the developmental orientation of MR/DD services conflicts with the care-oriented goals of traditional, geriatric nursing home services. Congress recognized this distinction when it initially authorized reimbursement for ICF/MR services by: (a) defining the purpose of such a facility as the provision of health or rehabilitative services for persons with mental retardation or related conditions; and (b) requiring that a certified facility furnish its residents with "active treatment" (Section 1905(d), Social Security Act). The inclusion of "habilitation" in the list of services a state may elect to cover under a Section 2176 waiver program is another sign of Congressional recognition that the aim of LTC services for non-elderly recipients with severe disabilities differs from parallel service goals for elderly LTC recipients. Yet, federal Medicaid policy generally restricts eligibility for Title XIX reimbursable LTC services to persons needing the level of care provided in a SNF, ICF or ICF/MR and limits coverage to medical and remedial services specified in a state's Medicaid plan.

One manifestation of this conflict in goals is HCFA's longstanding regulatory prohibition against claiming Medicaid reimbursement for educational or vocational training services (42 CFR 441.13(b)). As a result of this policy, states are forced to either maintain eligible recipients with developmental disabilities in what, in many instances, are inappropriate non-vocational day activity programs or transfer them to vocationally-oriented programs where they must be fully supported through state-local resources.

If such clients simply required short term vocational rehabilitation services to facilitate the transition to full-time, independent employment, Medicaid support would be unnecessary; but, experience demonstrates that a significant portion of non-elderly, Medicaid recipients with severe disabilities require ongoing support at the job site and a sheltered living setting in order to be gainfully employed. State vocational rehabilitation agencies are not authorized under federal law to provide continual, post-employment services and, therefore, such clients are almost always rejected as "feasible" candidates for VR services. It begs the question to say that someone else should pay for the long term support services these clients need when, in fact, we know that the result will be to relegate such persons to non-vocational activity programs funded through Title XIX -- ironically at a significantly greater cost to federal and state Medicaid budgets. This results not only denies these individuals the dignity and self-worth associated with holding a job, but it also offers no hope of offsetting the costs of services by helping them to acquire and retain remunerative employment.

Last year Congress took a partial step toward correcting this existing inequity of Medicaid policy by adding a new statutory definition of the term "habilitation services". Under this definition, states may request authority to cover educational, prevocational and supportive employment services to participants in home and community care waiver programs, but only if they were previously institutionalized (Section 9502(a), P.L. 99-272). Prompt Congressional action is needed, however, to make this definition applicable to all DD recipients of Medicaid-funded LTC services (including ICF/MR residents and waiver recipients who were not institutionalized prior to entering the program). Already, HCFA officials are pointing to the limited scope of the new definition's coverage as evidence that Congress supports an absolute ban on Medicaid payments for educationally or vocationally related services to all excluded group of recipients[12]. We believe this interpretaion is a perversion of Congressional intent.

Third, the present organizational structure of HHS makes it extremely difficult (if not impossible) to develop and carry out a holistic strategy for reconciling Medicaid policies with national MR/DD service goals. As noted earlier, the Health Care Financing Administration spends close to $4 billion annually on Medicaid reimbursable services to recipients with mental retardation/developmental disabilities and, as such, has a pervasive influence on state-local policies governing services to this population. And yet, there is no identifiable organizational component of the agency charged with developing, reviewing and executing Medicaid policy as it impacts on these recipients; furthermore, few policy-level officials within the agency have had any prior experience in dealing with MR/DD issues. As a result, HCFA lacks a coherent set of policy goals governing Medicaid-reimbursable services for recipients with mental retardation/developmental disabilities, and a well-defined strategy for achieving such goals.

One example of this lack of a consistent, agency-wide policy direction occurred late in 1984 when HCFA, after Congressional prodding, launched an intensive series of direct federal ICF/MR "look behind" surveys. As a result of these surveys, a number of states were faced with the choice of either spending additional dollars to achieve full compliance with federal standards or reducing the facility's population in order to minimize the costs associated with continued certification. Since any added costs related to the maintenance of certification are certain to be reflected in higher Medicaid payment rates and, thus, high federal-state costs, the rational federal response would have been to encourage affected states to use the Section 2176 waiver authority to achieve desired depopulation goals, as an integral part of their facility correction plans. But, because the waiver program is managed by a different HCFA administrative unit than the look behind reviews, this option apparently was never seriously considered.

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[12] See, for example, HHS's response to the General Accounting Office's recent report, entitled Financing Health and Educational Services for Handicapped Children, GAO/HRD-86-62BR, July, 1986, pp. 28-30.

Congress finally intervened and gave the states the option of submitting a plan for achieving a phased reduction in the population of a non-complying facility over a maximum period of 36 months, as the result of amendment added during this Committee's mark-up of last year's reconciliation bill (Section 9516 of COBRA). However, HCFA still has not implemented this provision due to conflicting statutory language regarding the provision's effective date.

Medicaid is an extremely complex program and, therefore, Congress, almost of necessity, must delegate rather broad rulemaking powers to the administering agency. It is difficult to conceive, however, that an agency like HCFA, with a $100 billion budget, could ever modulate its policies to the programmatic needs of a specific target population such as recipients with mental retardation/developmental disabilities in the absence of an organizational focal point for such activities within the agency. We, therefore, recommend that Congress direct the Secretary to establish a unit within HCFA to oversee the development and execution of agencywide policies as they impact on Medicaid recipients with developmental disabilities.

Finally, like the federal government, many states are not properly organized to plan and execute Medicaid policies as they impact on the delivery of services to recipients with mental retardation/developmental disabilities. In order to participate in the Medicaid program, a state, as part of its Title XIX plan, must designate a single state agency to administer services provided under the plan. At the same time, under the statutes of all fifty states, a mental retardation and/or developmental disabilities agency is designated to operate public institutions and administer community-based residential and day services for MR/DD clients. Because the statutory responsibilities and operational goals of these two units of state government are significantly different, problems are often encountered in attempting to reconcile the general statutory aims of the state's Medicaid program with its services goals for citizens with mental retardation and other developmental disabilities.

Since, to a large extent, a state is permitted to define the scope and organizational configurations of its own Medicaid program (within the parameters set forth in Title XIX of the Act and related federal regulations), any attempt to reform Medicaid policy as it impacts on recipients with developmental disabilities must address existing intrastate, as well as national barriers to progress. Methods of encouraging or mandating (either through federal law or administrative policy) the adoption of streamlined organizational structures and/or improved interagency cooperation/collaboration need to be explored.

III. STATE-LEVEL ILLUSTRATIONS OF THE IMPACT OF CURRENT FEDERAL MEDICAID POLICIES

Let me briefly illustrate a few of the policy dilemmas posed by present federal Medicaid policies by referring to the situation currently facing Michigan. In FY 1977, our State spent $132 million on services to persons with developmental disabilities, only $14.8 million (or approximately 11%) of which was devoted to community services. The remainder was used to support the operation of twelve state institutions housing over 6,000 persons with mental retardation.

During the intervening years, we have closed four state institutions and are now in the process of closing another. The total number of residents remaining in state facilities today is 1,850, which means that we have reduced the population by over 70 percent compared to the 1977 census. Meanwhile, our budget for community services has grown by almost tenfold (to $142 million) and the number of persons served in various types of community programs has risen from 978 in 1977 to over 6,000 today. Currently, Michigan has 3,250 ICF/MR-certified beds -- 1,850 in state institutions and 1,400 in small, community-based homes. For purposes of the present discussion, it is important to point out that had Michigan elected to retain its 1977 institutional population in Medicaid-certified beds, the additional, annualized cost to the federal government (in 1985 dollars) would have been over $30 million more than our current Medicaid ICF/MR receipts.

Despite Michigan's strong commitment and enviable track record in building a viable community service system, we find ourselves, at this point, handcuffed by perverse incentives that are inherent in Medicaid policy. Let me explain.

Even though the cost of community residential services runs an average of 40 percent less than institutional costs, every time we move a client out of one of our state institutions into a community residence, or divert an individual from placement in an institution, the cost in state dollars to Michigan is approximately $4,500 annually. Why? Because we receive 56 percent Medicaid reimbursement on behalf of institutional residents, compared to minimal federal assistance on behalf of clients in our non-ICF/MR community programs.

Prior to September, 1985, the disincentive effect of Medicaid's institutional bias was partially offset by the fact that the State had a Medicaid "freedom of choice" waiver covering community-based day services for mentally ill and developmentally disabled recipients. However, HCFA refused to renew this waiver program, because: (a) the program was deemed not to be cost-effective according to HCFA's calculation; and (b) HCFA officials said they had erred in permitting certain coverages under the original waiver.

To offset the loss of the waiver, Michigan certified an additional 900 community ICF/MR beds -- despite our reservations about the long term efficacy of this approach. Furthermore, most of our new residential development over the next two years will be concentrated in community ICF/MR facilities; as a result, we expect to have 1,500 more ICF/MR beds on line by the close of FY 1987, plus about 300 beds per year will be added to this total in each succeeding fiscal year. The added ICF/MR cost to the federal government by the close of FY 1987 will be approximately $35.6 million, or considerably more than the cost of waive services last fiscal year.

Additionally, we have qualified approximately 8,000 adults with developmental disabilities for clinic services under our state Medicaid plan. The majority of the costs associated with this population are reimbursed by Medicaid as long as the service components are not vocationally oriented. Since the State cannot afford to lose these revenues, we are forced to maintain eligible recipients in a dependency-oriented program, even though it is clear that a significant number of them could benefit from supported employment services.

Michigan is certainly not the only state whose choices are being perversely influenced by existing Medicaid policies. Therefore, if I could leave one message with the Subcommittee, it would be this: failure to grant the states increased flexibility in managing Medicaid long term care funds will result in increased federal costs, not cost containment. Unfortunately, it also will mean *that we will be able to offer services to fewer eligible* recipients in settings which foster continued dependency, rather than integration into the mainstream of society.

IV. PRINCIPLES FOR REFORMULATING MEDICAID POLICIES AFFECTING MR/DD RECIPIENTS

Let me close by offering a list of several general principles which we hope Congress will observe in any attempt to restructure federal Medicaid policies as they impact on recipients with developmental disabilities:

1. Federal, state and local governments must share the responsibility for assuring that every American with disabilities has access to basic education, rehabilitation, and habilitation services in a setting most conducive to his or her growth and development. The type, scope and length of services provided by government must vary according to the individual's needs. In the case of certain persons with severe disabilities -- including many individuals disabled since birth or early childhood --the need for such assistance is likely to continue for the remainder of their lives. The goal of all services must be to help the individual with disabilities achieve the maximum degree of self-sufficiency he or she is capable of attaining. While the prudent use of available tax resources must be a primary consideration in organizing and delivering services to persons with severe disabilities, the needs of each individual, rather than the short run fiscal consequences, should determine the type of services he or she receives, as well as the setting in which they are provided.

2. Federal policies should not be allowed to impede, however inadvertently, the flexibility of state governments to use federal revenues in accordance with a comprehensive, long-range strategy for delivering services to persons with mental retardation and other developmental disabilities. Historically, the states have assumed primary responsibility for the delivery of publicly-supported services to persons with mental retardation. The growing involvement of other levels of government -- especially the federal government -- during the 1960's and 1970's has greatly enhanced the quality and accessibility of services to this target population. However, this trend has also spawned a new set of problems, including added costs and rigidities associated with overly prescriptive federal laws and regulations; but, the elimination of non-productive federal statutory and regulatory constraints should not

be used as an excuse for withdrawal of federal aid, as repeatedly proposed by the Reagan Administration in its plans to cap federal participation in Medicaid costs. Nor, is it possible for the federal government to fulfill its partnership responsibilities without evolving an effective means of reconciling cross-program differences in policies which impede state governments' capacity to develop and implement comprehensive services for their citizens with developmental disabilities.

3. Both federal and state policies should encourage the development of a pluralistic system of service alternatives which are tailored to the individual needs of various sub-groups of clients with mental retardation/developmental disabilities. If there is one overriding lesson to be learned from past failures in public policy, it is that no single living or programming setting is right for all persons with developmental disabilities, given the wide variation in the ages, functional capacities and limitations of the affected target population. Therefore, as states attempt to rectify their past over-reliance on large, isolated public institutions, both federal and state policy should attempt to stimulate a balanced continuum of residential and programming alternatives (e.g., group homes; apartment units; specialized foster family homes; in-home support services; respite care, etc.) for citizens with developmental disabilities. Similarly, in the area of daytime habilitative services, the emphasis should be on providing a broad range of programming options (infant stimulation and early invention services; school-based programs; adult activities services; sheltered workshops; on-the-job training, supported employment, etc.). The overall goal of federal and state policy, therefore, should be to create a service system which: (a) uses finite tax resources in the most efficient and economical manner; (b) facilitates the movement of clients to more appropriate settings, as their needs change; (c) avoids having public policy become the captive of any single provider interest group; and (d) enables and encourages persons with disabilities to become more self-reliant.

4. States should be encouraged by federal policy to establish a continuum of financing mechanisms and reimbursement schedules appropriate to the alternative forms of programming they offer for persons with mental retardation and other developmental disabilities. In order to accomplish this objective, it will be necessary to eliminate federal disincentives to the development of appropriate service alternatives as well as built-in incentives to use high-cost settings.

The addition by Congress of the Medicaid community care waiver authority, permitting the Secretary of Health and Human Services to approve state requests to fund non-institutional long term care services for certain Title XIX-eligible recipients, was clearly a step in the right direction. However, experience with the waiver program to date simply underscores the need for permanent statutory authority to cover home and community care services under state Medicaid plans.

5. Families should be encouraged to maintain their children with developmental disabilities at home, whenever possible. Explicit federal and state policies should be aimed at minimizing the excessive financial and emotional burden of raising a child with severe disabilities, through the selective use of cash subsidies, tax credits/deductions and supportive services to families of such youngsters. The long range savings fully warrant the adoption of such policies, whether one measures costs in economic or social terms.

6. States should be encouraged to develop systemwide management structures capable of assuring the effective and efficient delivery of services to clients with mental retardation and other developmental disablilities. Federal policyshould not impede efforts by the states to develop an integrated approach to organizing and delivering services, establishing payment rates and assuring quality, which cuts across specific federal funding streams. Over the past two decades, many states have instituted a county or regional system through which a comprehensive array of day and residential services are delivered to persons with mental retardation and other developmental disabilities. In addition, considerable effort has been directed toward establishing systemwide management reforms to increase the capacity of state/ local administrators to deliver MR/DD services efficiently and economically (e.g., the development of computerized management information systems and improvements in case management services).

   In recent years, however, the fragmented manner in which federal support is distributed has served as an impediment to the development of a rational, systemwide management strategy within a state.

* * * * * * *

On behalf of the Association, I want to express to the Committee my gratitude for this opportunity to offer the organization's views on this critical area of federal policy. If we can be of further assistance as the Committee pursues possible legislative solutions, I hope you will call on us.

STATEMENT OF JAMES D. TOEWS, ASSISTANT ADMINISTRATOR, OREGON DEVELOPMENTAL DISABILITIES PROGRAM OFFICE, SALEM, OR

Mr. TOEWS. Mr. Chairman and members of the committee, as a policy matter in the State of Oregon, both the legislative and executive branches of government strongly support the notion that all persons with developmental disabilities, regardless of the level of impairment, should have the opportunity to live and work and recreate in typical family, neighborhood, and community settings. And that is the clear policy goal, both in statute and in regulations, in our State. But we have a long way to go.

We still have one of the larger institutions in the country, a 1,100 bed institution. By the end of this 4-year period we will have moved about 500 people out, and we are continuing to expand services in the community for people to avoid the need for them to have to be deinstitutionalized.

But I have to say that we are continually frustrated by the policy kinds of contradictions and the regulatory contradictions that the Federal Government keeps putting in our way.

And I want to give a few examples of that. I want to focus on some specific kinds of things.

For example, we are working currently with a group of families whose children are in State institutions, and they are very, very receptive to the notion of taking their children back home to live with the family if we can put together a package of support services for those families. They resorted to institutional care simply because there was no other alternative.

Now in a couple of these cases, some of these families with children were very profound and multiple handicapped have said, these are the kinds of things we would need to allow our child to live at home with us.

In one particular instance, the family said that they needed respite care 1 day a week because their child is very multiply and very profoundly handicapped.

We are in the process of amending our waiver to allow ourselves to pay for those kinds of family support services, and respite care and those types of things, but we were promptly informed by our regional office, based on instructions from the central office, that under the waiver we could pay for respite care services no more than 30 days a year. So in that kind of configuration we would have to tell his family, we cannot meet your request to provide respite care 1 day a week because the Federal Government will not allow that as a reimbursable cost, when, in fact, by the family taking that child home from the institution, the cost of care will be cut by nearly two-thirds. That is the kind of barrier we face day in and day out in implementing community based services for this population.

There are many other barriers we face. We face the barrier of double funding when we convert from an institutional to a community based system. In a sense, you have to double fund the system for a period of time. Fixed cost remain in the institution; conversion cost—startup cost—are needed in community programs.

Now on top of that, we have the continued pressure to both improve and expand services in our institutional programs as well.

Several years ago because of threatened decertification in our State institutions, we pumped in another $14 million in our large institution. At this time, the U.S. Department of Justice would like us to sign a consent decree that would add another $22 million a year to our State institution, when, as a policy matter, our State hasn't really decided we want to dismantle institutional services.

Furthermore, in new proposed regulations from HCFA, the whole scope of active treatment in institutional settings is being expanded. And as Ben, my colleague, indicated, the full panoply of active treatment services are not necessarily needed by all the individuals. Everybody gets painted by the same broad brush, and they receive those services whether they need them or not.

And, in fact, our experience has shown that the ability to place somebody in a small community setting is not a function of the prior training they have received. It is a function of how we can creatively design and fund the community service system to meet that individual's unique needs.

Finally, there are many other issues that I could get into, but the recommendation I would make is that we absolutely have to remove the institutional bias in the Medicaid Program. That is the first criteria. We need to assist States with the dilemma of double funding that occurs.

Finally, I would say with the Medicaid and the waiver program, what we face is a very onerous process of regulatory control that is process oriented. It is not outcome oriented. And I think as we look at reform in the system, we need to articulate what the outcomes are going to be, and then look at how we design and fund services to achieve those outcomes. And that the monitoring for quality of care and that type of thing be based on outcome and not on a lot of regulatory process kinds of issues.

Thank you very much.

Senator DURENBERGER. Thank you very much.

[The prepared written statement of Mr. Toews follows:]

Testimony on

MEDICAID FINANCING OF SERVICES FOR DEVELOPMENTALLY DISABLED PERSONS

Presented to the

SUBCOMMITTEE ON HEALTH
SENATE COMMITTEE ON FINANCE

September 19, 1986

INTRODUCTION

My name is James David Toews. As Assistant Administrator of the Mental Health Division of the Oregon Department of Human Resources, I direct the Office of Programs for Developmental Disabilities. This office, with a biennial budget of over $150 million, oversees all community-based programs in Oregon serving over 7,000 persons with developmental disabilities and their families. These programs include community residential services, sheltered workshops, day activity centers, supported work, early intervention, parent training, case management, family support, and services to 1,240 persons residing in state-operated institutional settings.

BACKGROUND

The state of Oregon has adopted a clear policy direction regarding services to its citizens with developmental disabilities. Legislation adopted in 1981 specifies that the primary system of care and training for all persons with mental retardation and developmental disabilities shall be located in community settings. This legislation further requires that the state:

- o Develop biennial plans to reduce the number of persons served in state institutions;
- o Propose biennial plans to develop community services to accomodate all persons coming out of state institutions, and to further prevent unnecessary institutionalization of persons with developmental disabilities;
- o Plan the location of services for these individuals in proximity to family, friends and home communities; and
- o Consult closely with families in the design and location of community services for the disabled family member.

In 1985, the Oregon Legislature reaffirmed this policy direction by adopting additional legislation specifying that:

- o All community services shall be designed in a manner that enhances the "independence," "productivity," and "integration" of persons with developmental disabilities receiving those services (definitions for these terms were taken nearly verbatim from the Federal Developmental Disabilities Act); and

- All persons with developmental disabilities receiving community services shall be assessed annually to measure the degree to which their "independence," "productivity," and "integration" has been maintained or increased as a result of receiving those services. These data are to be aggregated, analyzed, and published for biennial legislative review and public inspection.

Since 1970, the institutional population in Oregon has decreased from 2,847 to 1,240. During this time two of three large state institutions have been closed, and community services (vocational, residential, early intervention, etc.) have been developed for over 2,900 persons with developmental disabilities.

By the end of this biennium (1985-87), community services will have been developed to decrease the population in Oregon's large remaining institution by another 375 persons. Planning is already underway to continue this institutional phase-down in subsequent biennia.

Population and fiscal trends associated with Oregon's institutional phase-down and community service development are displayed in attached Figures 1.1 to 1.4. Since 1975, the investment in Oregon in the growth of home and community-based services has increased from $4 million to $65.7 million, reflecting a 1,600% increase. It is particularly noteworthy that this growth has continued in a time period when Oregon's economy has suffered a severe and chronic downturn.

ISSUES/PROBLEMS

Despite Oregon's commitment to dramatically decrease its institutional population in favor of home and community-based services, the actual planning and funding of these services have been frustrated at many levels by federal policy, regulatory and administrative contradictions. Examples of these contradictions are:

- The ICF/MR and Home and Community-Based Waiver Programs are anomalies within the overall Medicaid program whose intended purpose is the provision of medical services to needy Americans. As such the funding of services for people with developmental disabilities is badly skewed toward an institutional and medical bias that sharply contradicts the developmental orientation of the developmental disabilities service system. Additionally, administrators of the Medicaid program lack the expertise and philosophical commitment to assist states to move toward home and community-based service systems that reflect a developmental value-base.

- The renewed vigor of the Health Care Financing Administraton to "up the ante" in enforcement of ICF/MR regulations, and expanding the scope of those regulations in new proposed rules, is and will have a detrimental effect on the overall field of developmental disabilities. The net result of these efforts is the massive infusion of new resources into institutional environments, coming at a time when many states, like Oregon, are attempting to dismantle institutional services.

- In Oregon, the average daily cost per person for instituional services has accelerated from $51.25 to $96.82 since 1979. This expanded investment in institutional care has resulted almost exclusively from Federal regulatory activity. Adding new dollars to the institution compounds the fiscal burden states already face in transitioning services from institutional to community settings. The transition process requires a time period of "double-funding" during which insitutional fixed costs are still unavoidable, but vast new resources must be expended for start-up of new community services (e.g., acquisition, modification and furnishing of community homes, staff hiring and training, etc.) In a state like Oregon, already saddled with a poor economy, this excessive layering of old and new costs makes the transition process extremely difficult.

o The Civil Rights Division of the U.S. Department of Justice, responsible for implementation of the "Civil Rights of Institutionalized Persons Act," (CRIPA), is pursuing a similarly misguided policy direction of forcing vast new expenditures in institutional programs. The Division has recently filed suit against Oregon demanding the massive infusion of new staff into our large remaining institution at a cost of $22 million additional a year. This again compounds the "double-funding" dilemma described above.

o Federal pressures to increase institutional spending, coupled with the "double-funding" faced by states choosing to reduce institutional populations by developing new community services, exacerbate another serious problem. Oregon, like many other states, has large numbers of disabled persons living at home with their parents receiving no services or support. This waiting list of unserved persons is fueled each year by hundreds of severely handicapped children graduating from public school needing vocational services and support. With funding tied up in institutions, or in the effort to downsize insitutions, waiting lists of unserved persons will grow unabated, creating even more pressures to institutionalize these individuals, thereby creating and expanding a vicious cycle.

- One of the enduring myths perpetuated by Federal bureaucracies and many professionals in states as well is that the requirement and provision of "active treatment" to institutionalized persons with developmental disabilities will expedite their movement into home and community-based services. Active treatment requirements in Federal ICF/MR regulations call for training, habilitation and health-related services to disabled persons which will facilitate their move toward greater independent functioning.

Professionals do not debate the fact that active treatment requirements in ICF/MR regulations have significantly improved the quality of institutional care over the past 10 years. However, the question remains whether "active treatment" is a precondition for successful movement of institutionalized persons into community programs. Our experience tells us that it is not. The full panoply of active treatment requirements paint all institutionalized residents with the same broad brush. Services must be provided whether they are individually needed or not. Additionally, many of the active treatment requirements bear no relevance to preparing residents to adapt to community living. And the training requirements that are relevant can just as easily be met in small, community-based programs. Institutionalized

> persons need not be trained or "made ready" for community placement. Successful integration of a disabled person into a community setting is not a function of the degree of that person's prior training. Neither is it a function of that person's level or characteristics of disability. Rather, successful community placement is a function of the manner in which community services are designed and funded to meet the unique needs of each disabled person served. We now know that the service technology is available to serve all persons with developmental disabilities in community settings (regardless of level of disability, multiple-handicapping conditions, behavioral disturbances, etc.). And based on demonstration, we also know all such persons will benefit from community services. The remaining question, therefore, is how states can fund and replicate service technology broadly enough to transition all institutionalized persons into small community programs.
>
> Based on the assumptions above, it can be argued that states proceeding to dismantle institutional services be allowed to prioritize spending in development of community programs as opposed to the provision of "full" active treatment to institutionalized persons for whom placement in the community is planned within reasonable time frames.

The Home and Community-Based Waiver has been heralded as the answer to the institutional and medical bias of Title XIX requirements in the ICF/MR Program. Although the waiver program represents a significant philosophical commitment on the part of Congress, and although Congress has reaffirmed this commitment in the recent COBRA amendments, the Waiver

Program still has not lived up to its originally intended promise. Reasons include:

- The number of people eligible for waivered services is a function of the number of ICF/MR beds in a given state rather than identified individual needs.

- The "annual unduplicated number of individuals served" is one of the basic calculations of the waiver formula. However, this is a derived projection and one which bears little resemblance to state budgeting or typical service funding.

- Although states are supposed to be able to design their array of services under the waiver, flexibility has become an onerous task of justifying every variation.

- Even with state assurances of quality and cost-effectiveness, states are requested to provide an inordinate amount of detail about every step of the process.

- The administrative and fiscal reporting systems not only require new ways of collecting data, but also far exceed the requirements imposed on the long-term care system. A new breed of waiver specialists has been born just to deal with these systems.

- The waiver is "process" rather than "outcome" oriented.

- The odds of waiver approval depend on when the request was submitted and in which federal region the state resides. Federal responses vary greatly between regions and the rules keep "evolving" without regard for statute or regulation. (COBRA amendments helped somewhat, but there are still major problems with federal interpretations.)

- Because of the inconsistency with the federal government's response to waivers, states are concerned with the stability of future funding. Although the Administration espouses support, it continues to constrain states' efforts to expand the program.

SUMMARY COMMENTS AND RECOMMENDATIONS

In Oregon we believe that the following principles should guide the Congress and the Administration in deliberations on the future funding and design of services for persons with developmental disabilities and their families:

- All persons with developmental disabilities, regardless of the level or characteristics of their disability, can clearly benefit from community-based services.

- The array of community services should include:

    - In-home support services to assist families in maintaining their handicapped children in the natural home.

    - Early intervention services to prevent or ameliorate the initial effects of handicapping conditions in infants and young children of pre-school ages.

- Community residential programs in configurations absolutely no larger than family size.
- Vocational training and employment services that will allow even persons with severe handicaps to work in integrated workplaces with necessary support and ongoing supervision.
- Intensive Case Management to assure that community services respond perscriptively to individual and family needs.

- The failure to serve certain types of individuals in community programs (e.g., profoundly retarded, multiply handicapped, behaviorally disturbed, etc.) is the result of either inadquate funding or the underutilization of existing service technology. As such this failure cannot be justified by saying that certain disability characteristics preclude an individual's potential to live and be served in community settings.
- The planning and implementation of community services for persons with developmental disabilities must occur in close cooperation with their families. And despite the fact that deinstitutionalization efforts often face stiff parental opposition, the track record shows that families will overwhelmingly support appropriate community services once they are in place.

In accordance with the above stated principles, we believe that Congress and the Administration should proactively adopt a policy and fiscal direction encouraging and supporting states to phase-down large congregate care services. States should be given technical assistance and fiscal incentives to develop and expand an array of small community programs that are responsive to individual and family needs. Specific recommendations include:

- o Assigning administration of the ICF/MR and Home and Community-Based Waiver portions of Medicaid to a Federal agency whose primary focus is services to the DD population.

- o Passing a version of the Community and Family Living Amendments along basic philosophical lines expressed in S.873 and H.R. 2902.

- o Expressing clear Congressional intent that Federal agencies negotiate with states as equal partners in converting service systems to a community base, assuring that the rigid, overregulated, overperscriptive, and inflexible strategies that have characterized Federal implementation of the waiver program are not repeated.

- o Easing the transfer of resources from institutional to community service settings by allowing a relaxation of rigid "active treatment" requirements in ICF/MRs when such facilities are targeted for phase-down within reasonable timelines. This should include a negotiated process between Federal agencies and states to maintain adequate staffing and resource levels in an institution to assure the residents' basic health, safety and protection in the time period preceeding their relocation to community programs.

- Assisting states with start-up grants to mitigate the fiscal hardships of "double-funding" involved in converting from institutional to community-based programs.

- Allowing states broad flexibility in designing and funding an array of community services in exchange for a federal cap of long-term care funds for the DD population tied to indexing based on population growth and cost of living adjustments.

- Specifying a negotiated process between Federal agencies and states to research and document quality of life outcomes involved in converting from institutional to individual and family-based community services (e.g., along the lines of Temple University's longitudinal study of the impact of phasing-down Pennhurst, etc.)

Overall reform in the funding and design of services for DD persons needing long-term care and support is desperately needed. Urgent action, clear policy direction, and courageous leadership is required of Congress and Federal Agencies to assist states in this endeavor.

Thank you for the opportunity to testify on these issues.

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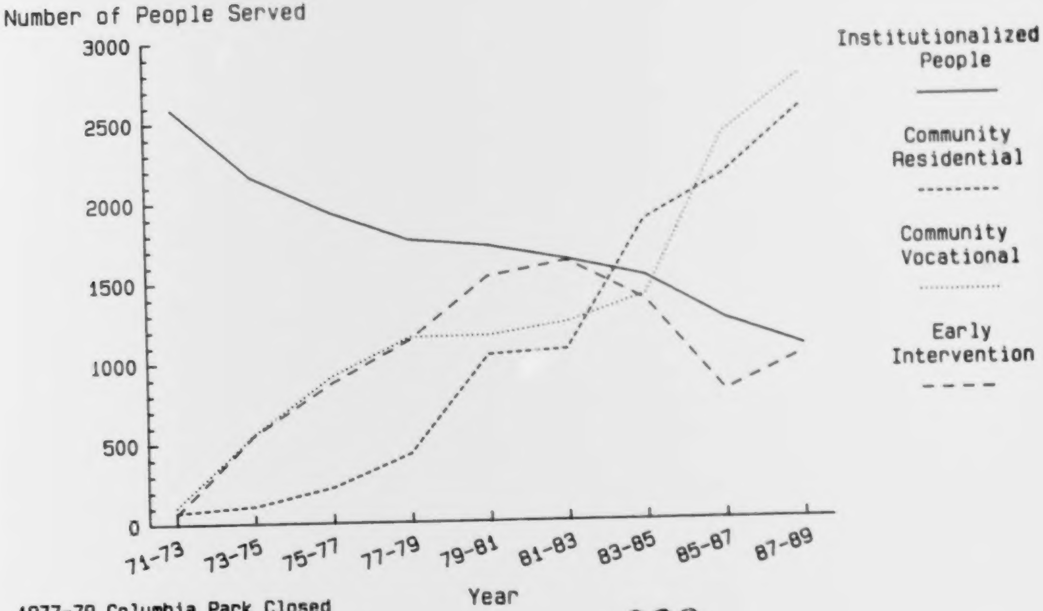
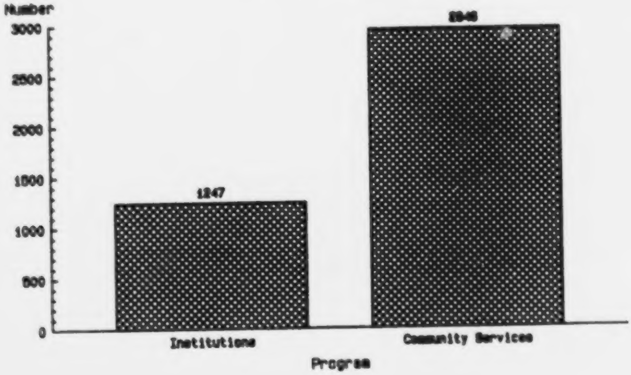


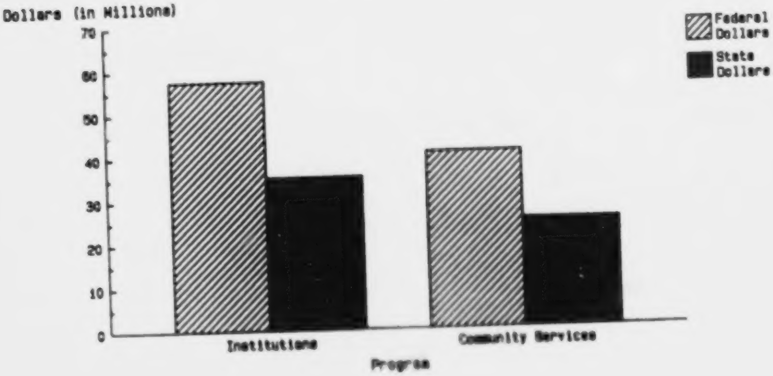
Biennial ADP

1977-79 Columbia Park Closed
1983-85 EOTC Closed
1985 Fairview Downsizing Began

Figure 1.3



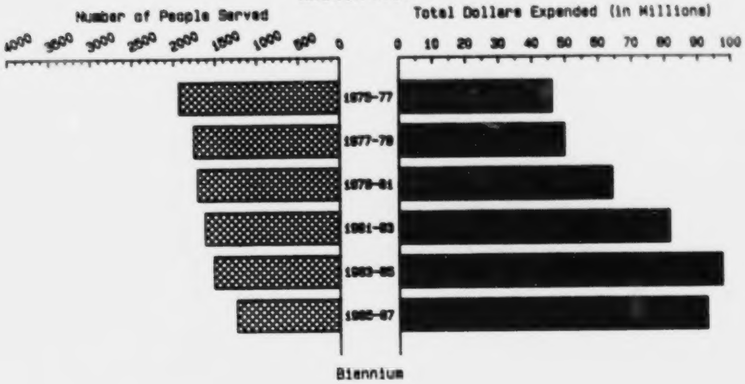
Total Number of People Served
1985-87 Biennium



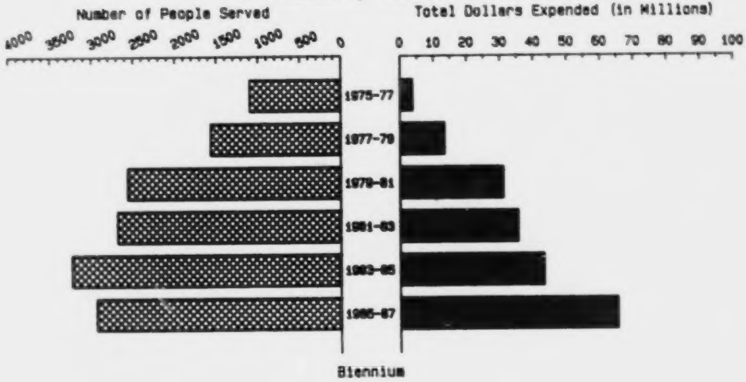
Federal and State Expenditures
1985-87 Biennium

Figure 1.4

Biennial Summary
Total People Served and Dollars Expanded
- Institutions -



Biennial Summary
Total People Served and Dollars Expanded
- Community Services -



Senator **Durenberger**. Mr. Skarnulis.

STATEMENT OF EDWARD R. SKARNULIS, PH.D., DIRECTOR, MENTAL RETARDATION DIVISION, DEPARTMENT FOR HUMAN RESOURCES, STATE OF MINNESOTA, ST. PAUL, MN

Dr. **Skarnulis**. Thank you, Senator Durenberger, and members of the Subcommittee on Health. I am pleased to have this opportunity to testify on behalf of the Department of Human Services in the State of Minnesota regarding Medicaid finances for children and adults with developmental disabilities.

As you know, Senator Durenberger, Minnesota has a long history of involvement in this program. According to a recent study commissioned by Lewin and Associates, Minnesota has one-eighth of all of the ICF/MR facilities in the Nation.

Our written testimony which you have received contains a variety of facts and figures about our use of Medicaid that we hope will be of some assistance to this subcommittee and perhaps some other States as well.

What I would like to do in my brief oral testimony is talk about real live human beings who illustrate the points that were made in the testimony we submitted.

There is a couple whose names are Dean and Tina Barr, who live about a mile from me in Scandia, MN who called on me a few weeks ago. I suppose because I am the State director of Mental Retardation Services they thought I might be of some help to them. Their son, Jason, fell into a backyard swimming pool April 10 and was not discovered for 10 to 15 minutes. He has all the medical labels that would normally classify him as among the most handicapped children in any of our institutions. He doesn't walk, he doesn't talk, he doesn't seem to be able to track movements with his eyes, he doesn't seem to respond to his environment at all.

Dean is a CPA in St. Paul who has been struggling to get through the anguish of what has happened to his adoptive son. He and his wife, Tina, are trying to find the strength to support each other and keep the family intact. And while they are doing this, they are trying to reach out for services for their child. They are ineligible for many programs, however, because their family income is too high.

Now if they want to place their son outside the home, their family income is not a problem. But to keep him at home, which is what they want to do, they will have to wait until there is an opening in Minnesota's Home and Community Based Waiver Program. Based on current allocations that we have, that eligibility is unlikely for at least the next year and maybe 2 or 3 years.

A friend of mine, Roger Deneen, is executive director of a 46-bed ICF/MR in Wayzata, MN. Roger has attended about every conference on mental retardation that he can attend. He has talked with parents of the people he is serving. Every time we had visiting consultants in the State, he picked their brains and concluded, correctly I believe, that a more normal integrated residential alternative for each of the people he serves is not only possible but preferable in 1986.

Unlike other institutional providers who seem to be devoting their energies to resisting closure, Roger has been given a directive by his board to move as quickly as possible to closure of the 46-bed residence.

They are struggling—his board is—to find alternative funding for those 46 human beings. They want those people to live in ordinary housing, preferably housing which even the most severely handicapped person can eventually own, in typical neighborhoods throughout the Minneapolis area. There is no funding mechanism available at this time to allow his board to close that small institution and absorb the interim operating costs which would be necessary, or to accommodate the cost of finding alternative uses for the building, let alone find the alternative sources of funding such as the community care waiver for those people to move into.

My daughter works in a day program for adults in Minneapolis. I would like to say that it is a real work program of the sort that David Mank talked about, but under Medicaid that sort of real work is discouraged. She was out last Wednesday with a young man from a nursing home, a 35-year-old man, and this was the first time he had ever been in a grocery store, the first time he had ever seen cantelope and zucchini and all sorts of things, and he was excited beyond belief.

Unfortunately, he cannot live in the community, not because we couldn't provide the service, but because the waiver formula depends on cost savings which are not possible with people who are in low-cost nursing home facilities.

In summary, I want to say that Medicaid needs to give States freedom to allow for more normal living and working and leisure time alternatives. That must be done in a value framework that assures integration, but is not so prescriptive or symplistic that it assumes that all people require certain levels of cost which ignore a basic strength of the family and neighborhood to support the person.

Thank you.

[The prepared written statement of Dr. Skarnulis follows:]

STATEMENT SUBMITTED TO THE UNITED STATES COMMITTEE ON FINANCE, SUBCOMMITTEE ON HEALTH REGARDING MEDICAID FINANCED SERVICES FOR CHILDREN AND ADULTS WITH DEVELOPMENTAL DISABILITIES (SEPTEMBER 19, 1986 HEARING)

BY

DEPARTMENT OF HUMAN SERVICES
STATE OF MINNESOTA

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I. INTRODUCTION

Over the past decade, Minnesota has been in the forefront of innovative efforts to provide dignified care and habilitative services for persons with mental retardation. In addition to traditional ICF/MR residential services, the state supports a variety of community-based services including semi-independent living services (SILS), family subsidies, day habilitation programs, home and community-based waivered services, and various work and educational programs.

Minnesota was one of the first states in the nation to use the Medicaid ICF/MR program as part of an aggressive plan to deinstitutionalize persons with mental retardation and to create community-based residential and service alternatives. During the 1960's, over 6,000 mentally retarded persons lived in Minnesota's state hospitals (regional treatment centers). By 1977, Minnesota had developed 121 ICFs/MR compared to less than five per state in the rest of the nation. In the summer of 1986, the regional treatment center population was under 1800. A consent decree emanating from the case known as Welsch v. Levine, No. 4-72-451 (September 15, 1980), required further reduction in regional treatment center populations. To meet this mandate, the legislature stressed transferring regional treatment center residents to ICFs/MR and encouraged development of new ICFs/MR.

Although the population of regional treatment centers in Minnesota continues to decline, the total number of persons with mental retardation in long-term residential care settings, both in regional treatment centers and in the community, has increased steadily in recent years. In 1978 the average population in treatment centers and community facilities was approximately 6300. By June 1985 it had increased to more than 7,100. The per capita (per 100,000 persons) utilization of regional treatment center and community-based ICF/MR beds in Minnesota has steadily increased from 146.9 in 1977 to 178 in 1985.

Minnesota continues to be one of the highest state users of ICF/MR services in the nation. In fact one-eighth of all the ICFs/MR in the nation are in Minnesota. Minnesota has more ICF/MR beds owned by for-profit providers than any other state. By the end of 1985, there were approximately 338 community facilities in Minnesota, certified to serve 5,418 children and adults. In addition, the seven regional center's beds were certified to serve 2,108 persons with mental retardation.

The cost of these programs is high. In 1982 total state expenditures on services for persons with mental retardation (including state institutions but excluding public schools) totaled over $175 million. In 1987 the estimated Medicaid costs for the ICF/MR and Developmental Achievement Center (DAC) program services alone are over $228.8 million. This is a function both of high utilization of ICF/MR services (Minnesota continues to lead the country in that regard) and high rates of reimbursement.

By 1983 there was growing evidence that the state had relied too heavily on the ICFs/MR for the care of persons with mental retardation. The development of new community ICF/MR beds had already passed the 1987 goals outlined in the Department of Human Services Six Year Plan. Staff of the Department of Human Services, the Department of Health, and ICF/MR providers estimated that 10 to 20 percent (500-1000) community clients should be moved to other more independent settings. During this same period, the Governor's Planning Council on Developmental Disabilities also took a look at policy alternatives for serving persons with developmental disabilities during the 1980's and published their findings in Developmental Disabilities and Public Policy, a Review for Policy-Makers (January 1983). This report stressed the need to develop alternatives to ICF/MR care, but recognized that the development of service alternatives is directly linked to the availability of state and federal funding. As a means of addressing this problem, the Council and the Legislative Auditor recommended that the state apply for a waiver under section 2176 of the federal Omnibus Budget Reconciliation Act of 1981. The waiver would enable Minnesota to receive the same rate of federal financial participation for providing an array of less costly home and community-based services as the rate for ICF/MR services, as long as the persons served would otherwise require placement in an ICF/MR.

These recommendations were debated by the 1983 Legislature which then passed Chapter 312 of Laws of Minnesota, 1983 which authorized the Commissioner of Human Services to apply for a Title XIX waiver to provide home and community-based services to persons with mental retardation and to promulgate emergency and permanent rules to implement the waiver. A moratorium on development of community-based ICF/MR beds was included in this legislation.

The policy consensus at both the federal and state level was that limited resources must be targeted to an array of services if we were to provide quality care for persons with mental retardation in the least restrictive environment consistent with their care needs. If a state wants to encourage an array of services to best meet the needs of the persons with mental retardation, public investments must be carefully targeted to achieve maximum benefit to the clients within the constraints imposed by limited resources.

Minnesota is obviously well qualified to reflect on the strengths and weaknesses of Medicaid. Without Medicaid we would not have the level of services available in our state for people with developmental disabilities and their families. As Rutherford Turnbull, immediate past president of the American Association on Mental Deficiency (AAMD), pointed out in his presidential address (Denver, 1986): "Money reflects policy and policy drives money." We are well aware that the attention this population receives is at least in part related to the economic impact of their service delivery system. We are also aware of some paradoxes. For example, we have learned that less expensive alternatives may not be less desirable ones. Our state's strategy in 1983 was one of moving people from state institutions, to community ICFs/MR to more independent or homelike waiver settings (a "continuum" approach). In the past two years we have seen that such an approach is not necessary. Sixty children and adults of the 209 moved from our regional centers last year, have moved directly from the regional centers into waiver settings. A January report of client movement analysis in the institutions indicates that at least 25% of those people are authorized for the waiver.

The changes in programs in Minnesota can be summarized simply as a shift from bricks and mortar to a program of integrated community services. Separate buildings, that is, state hospitals, ICF/MR community facilities, DAC and sheltered workshop buildings have been key ingredients in our current system but our priorities are gradually, and slowly, shifting to the use of ordinary housing, generic services and employment programs in the everyday work place. Persons are integrated into the local community where the entire community can share in the ownership of the programs and they can maximize the use of existing services. Persons need specialized services, not specialized buildings.

While there has been demonstrable progress in moving people into ordinary settings, there are problems which remain to be addressed. Nearly $100 million of state and federal money is budgeted on behalf of the 1,800 people in our state regional centers, and approximately $130 million will be spent on the 5,200 people in community-based ICFs/MR. Of that latter amount, 46 percent, or $60 million, is spent on community ICF/MR facilities serving 16 or more people. Thus, of our total expenditures of $230 million in institutional and community residential services, as much as $160 million is being spent on people in large congregate care environments. This occurs despite nearly two decades of attempting to reverse that bias, in a state that is committed to developing integrated, community service systems for children and adults with mental retardation. Why is this so? One reason is that state and federal fiscal disincentives exist today and have existed since the inception of Title XIX funding for mental retardation services. Even the community care waiver, which is an excellent alternative and which Minnesota is aggressively using, does not allow movement of all people from institutions to family-scale housing. It continues to be viewed by parents and providers as temporary due to its "waiver" status and requires states to demonstrate cost savings as part of the formula for approval by the U.S. Department of Health and Human Services. It is, therefore, not always a true alternative to institutional placement. In describing Medicaid, Dr. Turnbull refers to "a presumption in favor of medical, institution-based services to one which favors a developmental, community-based system... a public policy torn between altruism (doing what's "right" for people) and custodialism, which maintains dependency."

The following examples from staff in our Department illustrate individual problems with current Medicaid policies:

The parents of a ten year old child called the Department of Human Services to inquire about facilities in the state which could serve their daughter. They wished to keep their daughter at home, but were told by the county case manager that money was not available, and that they should place their daughter in a secure environment - an institution. After visiting these facilities, the parents requested that their daughter live at home, with respite care and other in-home supports. Shortly thereafter, the daughter ran away from home, was sexually assaulted, and was placed in a state institution. After two years in the institution, we were finally able to use the Home and Community-Based Waiver to develop a foster home where today she remains, successfully attending school, visiting home and vacationing with her parents. Obviously, this child experienced two years of clearly unneccessary removal from her community.

In the past, large community residential service providers with a history of marginal performance were sometimes "maintained", or at least license revocations were approached cautiously, because of a lack of appropriate alternatives if closure were to occur. Even more perverse, however, is the case of conscientious providers of services wishing to voluntarily downsize or close. We currently have five large community ICFs/MR, serving 50-150 people each, which want to change their services but are unable due to their inability to sustain the interim costs associated with downsizing or closure. No timely mechanism exists to fund such closures to adjust the amount of conversion activity needed based on voluntary or involuntary decertification.

One specific example of such a provider is Hammer Residence of Wayzata, MN whose Board of Directors unanimously voted to close their 46 bed facility. The Executive Director, Mr. Roger Deneen, has worked diligently, talking with the county, the state, facility staff, and parents to bring about an agreement which will guide the orderly process of moving the residents into more appropriate, individualized residential environments using existing housing in the community. Everyone is convinced of the virtue of the plan. But, there are no waiver openings to move the people into, nor are there funding mechanisms available under Medicaid to allow this non-profit group to absorb the interim operating costs which will be necessary, or to accommodate the costs of finding alternative uses for the building.

II. RECOMMENDATIONS

No attempt will be made here to re-state some of the excellent analyses already prepared on this subject. With few changes, for example, we feel that the Robert Wood Johnson Foundation National Study Group on Medicaid Strategies conclusions, outlined in their January, 1984 report, remain valid today. Similarly, the National Association of State Mental Retardation Program Directors (NASMRPD), prepared an excellent set of "Guiding Principles for Evaluating Federal Long-Term Care Reform Proposals" and "Principles for Reformulating Inter-Governmental Roles." Mr. Ben Censoni, the Chairman of the Association's Governmental Affairs Committee has submitted those documents as part of the NASMRPD testimony. What follows are specific recommendations or areas of concern that are intended to complement the work cited above.

A. Common Need For Continuing Care

1. A simple federal block grant approach to financing continuing care services for persons with developmental disabilities (and other target groups, as well) does not account for the increasing need for continuing care services which states have experienced. While block grants are enticing to states because of their service and funding flexibilities, they frequently result in state refinancing of federal programs, loss of recipient entitlement, reductions in service levels, and an inability of states to respond to the needs of persons requiring continuing care.

2. One model for restructuring medical assistance proposes that the funding of services for eligible persons in both the aging and developmentally disabled populations be separated from medical assistance for acute care. Combined funding for persons within these two groups, aging and developmentally disabled, would be classified as "continuing care", as differentiated from acute care. Concern for our population of aging Americans is broad-based and its roots run deep. The opportunity to share in the well organized advocacy efforts of such a large and influential group is very appealing to those of us who work and advocate with a smaller and more diverse population.

The very size of the combined groups, and the aggregate funding necessary to provide needed care and services for both, offers the potential for greater stability and permanency in overall support and improved options for long-term planning. Certainly, a lesson that democracy teaches is that the size of a constituency can influence the continuity of services provided to its members. Further, persons with developmental disabilities share with many of their aging, non-handicapped fellow citizens a long-term need for care that provides for their basic requirements and protects their health, safety and human dignity. And, in time, persons with developmental disabilities - like all of us - may reasonably expect to join the ranks of aging Americans themselves.

Aging Americans and those with developmental disabilities do, then, have a common bond of need and a strong motivation to support medical assistance restructuring that unites them in a more clearly defined manner and continued funding of developmental disabilities with aging is arguably in the best interests of both groups. There are, however, additional factors to be considered in any such proposal.

Persons with developmental disabilities are found among all groups of the population, from the earliest to the most advanced years of life. Continuing care, in varying degree, is required by all persons with developmental disabilities eligible for medical assistance because of their disabilities. But, in addition, the vast majority of persons with developmental disabilities require services which assist and support them in developing new competencies, in enhancing existing skills and in reducing their dependency.

These services, commonly designated "active treatment and habilitation", provide the opportunities which each of us seeks in our own life . . . the chance to learn and to grow and to become more capable of controlling our daily activities and of enjoying the most precious gift of a free society — the right to choose.

Should medical assistance for persons with developmental disabiltiies and for the aging population be combined in a separate medical assistance funding component, a concept which we support, we urge that the term "continuing care and developmental services" be considered to describe it . . . and that the funding reflect both needs.

B. Eligibility

Medicaid services allow for voluntary funding of people with conditions other than mental retardation at this time. In order to assure equity, expanded coverage for people, based on functional criteria rather than clinical labels, is needed. Eligibility of persons with developmental disabilities for services within the continuing care area should be based on the presence of limitations in a person's ability to function independently. Functional limitations would be defined using the language of the amended Developmental Disabilities Assistance and Bill of Rights Act of 1975 (Public Law 95-602). All functional limitations would need to pose a "substantial handicap" to an individual's ability to function normally in society. Thus, "the term 'developmental disability' means a severe, chronic disability of a person which:

1) Is attributable to a mental or physical impairment or combination of mental and physical impairments;
2) Is manifested before the person attains age 22;

3) Is likely to continue indefinitely;
4) Results in substantial functional limitations in three or more of the following areas of major life activity;
   a) self-care
   b) receptive and expressive language
   c) learning
   d) mobility
   e) self-direction
   f) capacity for independent living
   g) economic self-sufficiency
5) Reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated."

The amendments of Public Law 95-602 change the focus of the definition from a categorical to a functional one. Thus, the definition no longer listed specific diagnoses that previously had been used to limit the definition to those impairments closely resembling mental retardation, but included any person with a mental or physical impairment that limits the person's functional ability in certain activities. Furthermore, the age by which a condition must manifest itself was changed from 18 to 22.

Care must be taken in developing the assessment procedures and instruments employed to determine whether a person has a "substaintial functional limitation" in any of the areas covered by the definition of developmental disabilities. The assessment procedures must measure meaningful skills, employ age appropriate materials, and take place in the appropriate environmental context. Otherwise the determination of whether a "substantial functional limitation" exists will become artificial and meaningless.

C. Case Management

Many states are moving to provide case management as a service under their state plan. It is the "glue" that provides continuity in services across providers and over time. Case management should be required for every applicant for services to assure an appropriate determination of eligibility and delivery of cost effective, high quality services. The role of the case manager should include at least the following critical duties:

1) Initial review of each person's application and arranging for the assessment of that individual's skills and need.
2) Determination of eligibility for continuing care services based upon the assessment results and whether they found the presence of substantial functional limitations.
3) Writing of an individual service plan in conjunction with the eligible person or their guardian which will meet the needs of that eligible person.
4) Selection or development of service providers to implement each individual's service plan.
5) Refinement and modification of the individual service plan based upon input from service providers.

6) Monitoring of services as they are implemented to ensure that such services are of high quality.
7) Periodic reassessment and service plan modification to meet the evolving needs of each eligible individual.

Evidence from research and Medicaid demonstrations indicates that case management is an important factor fitting service responses to individual needs, reducing unnecessary institutional care, controlling costs, and more efficiently managing public resources.

D. Individualized Service Planning

To ensure that the needs of eligible individuals are met, it is absolutely essential that services be designed for each individual. Only through such an individualized, "handcrafted" approach can the wide variation in individual need be appropriately addressed. Individual service plans must contain at least the following components:

1) A summary of the assessment results in each relevant area of basic life skills.
2) Identification of all services needed, including the type, amount, frequency of services.
3) The providers of each service.
4) The long and short range goals for each eligible person.
5) The methods to be employed in achieving each person's goals.
6) The evaluation procedures to be employed to determine whether progress has been made in achieving each goal.
7) The dates of future reviews of each individual's service plan.
8) The signature of each eligible individual, or their guardian agreeing to the individual service plan.
9) The signatures of the case manager and all service providers.

Each service plan should guide the expenditure of funds. Services which are listed in the plan will be paid for to the extent specified in the plan. Changes in service plans control and determine changes in expenditures.

E. STATEWIDENESS

In Minnesota, the administration of the Medicaid program for persons with mental retardation or related conditions is implemented through 87 county agencies. The capabilities of these county agencies to develop or change services varies significantly and as a result it may take three to four years to establish services on a statewide or comparable basis. It is recommended that a state be allowed to temporarily (up to four years) furnish services on less than a statewide or comparable basis, provided that such restrictions are part of an incremental strategy for accomplishing the goals of the restructuring. This provision would allow Minnesota to avoid the "all or nothing" effect of these basic Medicaid requirements during the initial stages of implementation.

F. CRITERIA FOR FINANCING

It is recommended that a maintenance of fiscal effort should be required at the federal and state levels. The formula used to determine the amount and distribute available federal funds must account for the increasing number of persons needing continuing care and be sensitive to the historical variations among states in their provision of continuing care services.

Financing policy must support programmatic policies and provide the flexibility to serve persons in a wide array of service settings based on their individually assessed needs. Ongoing stability of federal funds is essential to assure financial predictability of federal funding for continuing care services. Sufficient time must be allowed for states to adjust to new financing policies to assure that system changes are implemented effectively.

III. SUMMARY

A. Current Medicaid regulations limit flexibility in achieving program goals. For example, Medicaid only pays for fixed units of service in ICFs/MR, so that unbundling these services (paying for two days a week in an ICF/MR or one-half day habilitation) is not possible. Medicaid regulations also specify that ICF/MR reimbursement systems must provide rates which are reasonable and adeqate to pay the costs which must be incurred be economically and efficiently operated facilities. The focus is invariably not client-based or individualized under such a system

B. A more flexible, client-based reimbursement system is needed. Some professionals argue that each client has different needs and associated costs and that attempts to develop service levels blur these distinctions. Others argue that it is important to remember that service levels are not developed to prescribe specific treatment, (this must remain a function of the individual program planning process), but rather to create an administratively manageable number of payment levels. If each client's service level was to be reimbursed at a different rate, that would create a system with over 5,000 different rates in Minnesota. But, would this be best? Would it be less expensive, given our computer capability today, to allow a case manager to "build" a time-limited set of services, using software designed to guide that process?

C. We recommend a continuing care and developmental services Medicaid assistance area. There is a fear that if developmental disabilities is block granted, it will be an easy target for the type of capping done under Title XX. This population (developmental disabilities) is the most vulnerable, and remain dependent for the longest time, of almost any disability group. Unlike those in other long-term care categories, they are not "terminally ill". Unlike those needing acute medical care services (e.g., AFDC), they are neither cured nor do they grow up and move off the public rolls.

D. Permit use of MA to fund clearly cost-effective services. We have 250 families receiving state-funded stipends which are designated to help them maintain their sons and daughters in the natural home. Again, while the use of funds for this purpose is clearly cost-effective, it constitutes far less than the demand. The irony is that we will spend $50,000 per person per year in our regional centers rather than spend $3,000 per year to maintain those same people in their home. This condition is not new, nor is it unique to Minnesota. Since the massive infusion of Title XIX funds into institutional settings in early 1970's we have said: "Give us money to improve institutions in order to get people ready to live in the community." Then we find ourselves saying, "We'd love to refer people to the community, but there aren't any community residences available, or money to fund them."

A consultant firm which Minnesota hired recently to help develop an equitable reimbursement system noted that:

> Federal Medicaid requirements constrain what services can be paid for and how they must be structured. For example, federal Medicaid requirements constrain ability to pay for supported work in DACs. However, paying for ICF/MR, DAC, and waivered services through Medicaid saves substantial state and county resources and enables Minnesota to shift more costs to the federal government, providing more services overall. It must be decided whether program constraints imposed by Medicaid distort program goals to the point that the savings are not sufficient to warrant continuing to fund certain portions of the system, such as DACs, through Medicaid.

It would be nice if Medicaid re-structuring could enable us not to have to make that choice.

Senator **Durenberger**. Thank you very much.

I can't solve all those problems, but I have a thought for the friend of yours from Scandia who—was it his son who was found in the pool? You probably know Dana Kruse who is here today. And if you could get that boy to meet Jenny Kruse, who 4½ years ago drowned in International Falls—and I went to visit Jenny this summer—it would be kind of nice to get the two of them together at some point in time, and you can do it through SKIP, and I think Dana will share some of her experiences and the frustrations. And that is why I appreciate the fact that all of you would like to personalize your testimony as all of you could. And for those who cannot understand that those of us who are the so-called policymakers do share the opportunities that you do every day, we don't get it every day, but at least we do share the opportunities to meet some of these incredible families who have been provided with some unique opportunities during the course of their lives. And it is from those particular experiences probably as much as from the researchers who have testified here today that we come upon the public policy alternatives.

So let me express my appreciation to all four of you for the work that you are doing in your respective States and for your testimony here today. And let me again defer to my colleague from Rhode Island for specific questions.

Senator **Chafee**. Thank you, Mr. Chairman.

I just wanted to ask Mr. Toews one question. He said that what we have got to do in reforming Medicaid is to remove the institutional bias that you find in the Medicaid system. And, of course, we have had a series of points made here today. But could you just perhaps tick off some of the specific tilt that you find in favor of the institutional system, some of the points?

Mr. **Toews**. Yes, Senator Chafee.

Senator **Chafee**. Because you heard the administration testimony that, well, after all, we have got the waiver. And the waiver may be a little difficult to obtain, but we are moving in that direction, and so there is perhaps not as much a problem as you and I think there is.

Mr. **Toews**. Well, Senator Chafee, the waiver, which was sort of heralded as the alternative, I think—and many of us have pinned a lot of our hopes on that—but when you really look at the implementation of the waiver, I have never seen a process that is more regulated and more prescriptive and more paperwork bound than the waiver.

We have ended up in our State employing a whole bunch of waiver specialists who speak a language that I don't understand at all, and speak in formulas. And I am supposed to administer the program, but half the time I don't understand; that it has gotten so complex.

You have to get approval for everything. I mean, the simple issue I laid out about trying to obtain respite care services for a certain family who are willing to serve their child at home at less than half the cost in our State institution, and yet that is not yet deemed as an allowable cost. And yet the Medicaid Program will fully fund that person at $45,000 a year in our institution, providing a whole panoply of services that that person may or may not need.

And I guess when I talk about the institutional bias, the program overall is still facility driven. It is driven by very traditional notions of facility based services. When you look at the new proposed regulations for ICF/MR's, there were requirements proposed even for small programs, under 15 beds, that you had to have professional staff meetings with dentists and pharmacists and therapists and things like that present at those kind of meetings to develop the plan of care for that individual.

And, quite frankly, I think that from both a programmatic point of view and a fiscal point of view, I just think that is absurd.

So I guess those would be a few examples I would give of how institutionally biased and facility driven the whole program has evolved.

Senator **Chafee**. Mr. Censoni?

Mr. **Censoni**. On the same topic?

Senator **Chafee**. Yes.

Mr. **Censoni**. I guess the best way to explain it is, if I had a mind—I don't. I want to make that clear——

Senator **Chafee**. If you had a what?

Mr. **Censoni**. If I had a mind to—but I want to make it clear that I am not going to do this—to go back to Michigan and to set up a 100-bed ICF/MR, I could do so rather quickly. I would know the rules. I know that once I get into that facility, as long as I play those other rules, I am going to have ongoing funding. If I wanted to go back and deal with a hundred people in an institution, who are certified—you know, who are living in a certified bed—and wanted to take them home, there is no way for me to do that.

So that is the essence of the institutional bias. I mean, the rules of the game are clearly laid out for an institution. That is what they are built of.

So when you want to do things that are noninstitutional in nature, and the rules change—they are very difficult to get a hold of; they are very process oriented—you are not quite sure, you know, when they are going to change. And you do go from a very secure—and I put that in quotes because you can lose funding—you can go from a very secure funding base to a very insecure funding base in the community. And that is the essence of what we mean by institutional bias.

Senator **Chafee**. Miss Matula?

Ms. **Matula**. If I could add to that, Medicaid, of course, was begun as a health program. So a health facility, such as an ICF/MR, qualifies for most if not all of its costs to be paid. Those costs include room and board. Those costs include personal care that is not medical in nature.

In order to provide any service outside that health facility for the same client in the home or in another local facility, the waiver forbids room and board to be paid. That is number one. Now there is an institutional bias: The needs are still there, but they cannot be paid. You have to have a waiver to provide the kind of care that is less than medical.

So when we talk about waiver, we are talking about waiving the old health facility rule. We are talking about, in some States, waiving eligibility rules. And we can make the person eligible under the waiver without counting family income at home, but not if we did not have the waiver.

Senator CHAFEE. Well, yes. But the HHS's answer is, well, we will give you a waiver. What is your answer to that?

Ms. MATULA. You should not hold your breath waiting for it. [Laughter.]

Ms. MATULA. It takes a tremendous amount of stamina to apply for an initial waiver, and it takes the patience of a Saint to go through a renewal process.

Senator CHAFEE. Have any of you experienced a withdrawal of waivers? I mean, previously you had to come up every 3 years for waiver review.

Mr. CENSONI. Yes. We did lose our waiver in Michigan because we did not match the cost reduction requirement in the formula.

I want to caution you, we had a slightly different waiver than most States have, but it was the same concept. And in our case, the reason that we could not meet the formula on the cost was that there were two services included in our program by agreement—everybody agreed—that HCFA later decided we are not allowable under our waiver. So they took those costs and then saw them as excess costs and our waiver was not renewed. That is the kind of risk that I am talking about.

In other words, nobody said we did anything wrong. We played it by the rules. But because there was an error in the original computation in the original service arrangement that we all agreed we could make, we lost our waiver.

Senator CHAFEE. All right. Fine. Well, thank you. And Dr. Skarnulis gave us some examples of the tilt in his testimony. Thank you all very much.

Senator DURENBERGER. George?

Senator MITCHELL. Mr. Chairman, I have no questions. I thank the witnesses. I do have a statement that I would like to have inserted at the appropriate point in the record. And I apologize for missing the testimony of some of these witnesses.

Senator DURENBERGER. Is there objection to introducing George's statement in the record?

[No response]

Senator DURENBERGER. Without objection, it is so ordered.

I thank all of the witnesses for their testimony.

The next panel is three persons, Dr. Richard Scheerenberger, past-president and editor of the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded, Madison, WI; Bonnie-Jean Brooks, executive director, Opportunity Housing, Bangor, ME, and secretary of the National Association of Private Residential Facilities for the Mentally Retarded; and Peter Benner, executive director, council 6, American Federation of State, County and Municipal Employees, St. Paul, MN.

Dr. Scheerenberger?

STATEMENT OF RICHARD C. SCHEERENBERGER, PH.D., PAST PRESIDENT AND EDITOR, NATIONAL ASSOCIATION OF SUPERINTENDENTS OF PUBLIC RESIDENTIAL FACILITIES FOR THE MENTALLY RETARDED, MADISON, WI

Dr. **Scheerenberger**. Well I had submitted a few pages, so I won't repeat that.

There is certainly nothing occurring in the field in terms of promoting deinstitutionalization that is not being supported by the National Association of Superintendents and we continue to support it. We do intend to supporting the whole deinstitutionalization efforts, and have done so historically, a lot of us through our own institutional operations.

On the other hand, I think we have to express some concerns about the quality of some of the services that are being offered in the community. And I mention this only from the point of view of, if we are going to do it, for heaven sakes let's do it right.

Now I am a little surprised that I am here to represent the association because I have disagreed with title 19 since its inception. I think it was illy conceived and atrociously administered, and I have been consistent about that since 1974. But no one out here was too happy to hear it then, and I am not too sure too many are now.

So in one respect I certainly would want to support Senator Chafee 500 percent. And that is, if we are going to go community programming, get it out from under title 19 that is. Just forget the whole damned waiver bit. Just start a total new program. You will pick up the title 19 dollars.

Now if you take the State institutions today, the handwriting is on the wall. If there are no changes in the current trends—and I am talking about abortions, and I am talking about infanticide, and I am talking about community programming, and I am talking about an aging population—there will not be any need for State institutions in 30 years, because 80 percent of the population now in the State institutions are adults, profoundly retarded, who are going to be extremely difficult to accommodate in the community. It can be done, but I think, as some of you are involved in this realize, adult programming is a very sad state of affairs in this country and it is just nonexistent in many cases.

I would like to add that we are probably talking about a quarter of a million people, not simply the 100,000 that are in State institutions. One of the sidelights and damaging effects of this whole title 19 thing and some of the emphasis on deinstitutionalization is that mentally retarded people who historically would have gone to institutions, you will find them now in nursing homes, juvenile delinquency halls are just full of them, and have gone through all different types of alternative community arrangements. I estimate, conservative, that a hundred thousand are living in inappropriate other institutional settings.

Fifty percent of the people discharged from institutions since 1974 have, in fact, gone to another institution.

I remember somebody getting terribly excited in Illinois because they closed down an institution. I asked him if he looked at Kankakee. Kankakee had 90 people and they closed the institution. In a couple of months, Kankakee had 1,100 people, and everybody was excited because they closed an institution. We played musical institutions.

Like I say, if we are going to do it, let's do it right. And the best thing to do is set it up on its own program, because the State institutions will just keep getting smaller as it is growing unless there would be a huge switch entry, and you will pick the title 19 dollar up that way.

Thank you.

Senator **Durenberger**. Thank you very much.

George?

Senator **Mitchell**. Mr. Chairman, and Senator Chafee, it is my pleasure to introduce to the committee Miss Bonnie-Jean Brooks, who is here to testify on behalf of the National Association of Private Residential Facilities for the Mentally Retarded. Miss Brooks is Secretary of that organization, executive director of an organization known as Opportunity Housing, in Bangor, ME. She has had a very impressive record of participation in matters involving mental retardation in our State, and we are very proud of her, and I am pleased that she is here today to testify before this committee. Welcome, Miss Brooks.

[The prepared written statement of Dr. Scheerenberger follows:]

NATIONAL ASSOCIATION OF SUPERINTENDENTS OF PUBLIC RESIDENTIAL FACILITIES FOR THE MENTALLY RETARDED

September 6, 1986

TITLE XIX AND PUBLIC INSTITUTIONS FOR THE MENTALLY RETARDED

The availability of federal support to public residential facilities (PRFs) for persons who are mentally retarded has been highly instrumental to and, in many cases, the primary reason for the tremendous improvements in the quality of services currently provided.

First, Title XIX funds enabled states to increase staffing levels significantly. In 1965, for example, the staff:resident ratio was approximately 1:2; in 1981, it was 2.11:1 (Scheerenberger, 1965, 1981). Not only was the number of staff increased, but also the diversity of their training and experience. With improved salaries and working conditions, the turnover rate was reduced appreciably. It was not uncommon in the sixties for as many as 80% to over 100% of the staff to turn over annually. By 1980, that figure had dropped to less than 20% (Scheerenberger and Jones, 1981). This stability, in turn, rendered training and experience more meaningful, with a subsequent improvement in resident programming. Without federal funds, these gains would have never been realized.

Second, the issuance of regulations and "standards," combined with both state and federal surveys, produced both attitudinal and environmental changes which resulted in the elimination of unwarranted dehumanizing practices and the introduction of principles associated with the developmental model and normalization.

The fact that these changes have occurred is attested to by the recent series of federal "look-behind" surveys which generally concluded that, in all but a few instances, PRF services, while not always what one would completely hope for, were far from being as insidious as many had proposed.

It is fully recognized that the federal government, as well as most state governments, is confronted with a serious fiscal situation. Yet, it is imperative that continued federal participation be assured, especially since many PRFs receive more than 50% of their funds through Title XIX. If these monies were reduced, it undoubtedly would adversely affect services and programs since, in all probability, the states would not substantially increase their contributions. In fact, many states have already begun to cut positions solely for budgetary reasons (Scheerenberger, 1982).

Further, reductions in federal funding to PRFs might well prove equally disastrous to community programming. Most states have a firm statutory obligation to its institutional programs. The same is often not true for community efforts. Thus, if PRFs became seriously fiscally troubled, a state may decide to redirect its community support back to the institution. This, indeed, would be unfortunate.

Deinstitutionalization is at the crossroads. In the early days of Title XIX, many states, in order to participate in the program, placed many people into what, in essence, were alternative institutional settings, such as nursing and county homes. Over the years, approximately 50% of persons discharged from PRFS went to such settings. Also, to avert admissions to a PRF, these same resources

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were used (Scheerenberger, 1981, 1982, 1985). Thus, as both federal and state governments have come to realize, tens of thousands of mentally retarded people living in such inappropriate settings need to be relocated into more community-based, home-like environments. Combining this situation with the fact that over 90,000 developmentally disabled persons are graduating from high school each year, many of whom should be living away from home, developing an adequate number of group homes with the prerequisite support services and vocational opportunities presents a problem of considerable magnitude.

It is also evident that the existing population in the Nation's PRFS consists primarily of adult, multiply handicapped, severely and profoundly mentally retarded persons, many of whom present serious behavioral problems (Scheerenberger,1985). These individuals are going to be extremely difficult to place in an alternative non-institutional community setting.

In brief, the Association recognizes and appreciates the invaluable assistance of the federal government over the past dozen years and urgently requests its continuation in the interest of both residential and community programming. Also, it is not the intent of the Association through this statement to discourage, in any way, the continued advancement and promotion of sound community programming. In fact, it reconfirms its 1974 position: "The National Association of Superintendents of Public Residential Facilities for the Mentally Retarded fully supports efforts toward deinstitutionalization, institutional reform, and acceptance of a changing role" (National...,1974, p. 3).

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Respectfully submitted

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References

National Association of Superintendents of Public Residential Facilities for the Mentally Retarded. Residential Programming: Position Statements. Washington, D.C.: President's Committee on Mental Retardation, 1974.

Scheerenberger, R. A current census of state institutions for the mentally retarded. Mental Retardation, 1965, 3, 4-6.

Scheerenberger, R. Public Residential Services for the Mentally Retarded.(A series).Madison, WI: National Association of Superintendents of Public Residential Facilities for the Mentally Retarded, 1981, 1982, and 1985.

Scheerenberger, R., and Jones, S. Administrative Problems. Madison, WI: National Association of Superintendents of Public Residential Facilities for the Mentally Retarded, 1981.

STATEMENT OF BONNIE-JEAN BROOKS, EXECUTIVE DIRECTOR, OPPORTUNITY HOUSING, BANGOR, ME, AND SECRETARY, NATIONAL ASSOCIATION OF PRIVATE RESIDENTIAL FACILITIES FOR THE MENTALLY RETARDED

Ms. Brooks. Thank you.

Mr. Chairman, Senator Mitchell, and members of this subcommittee, I am not going to tell you who I am because Senator Mitchell already did that.

You have it in the copies of our testimony presented for the record a full description of our association and the community agency that I direct in Maine. In it you have a summary of the specific recommendations we made related to problems being experienced with Medicaid.

Mr. Chairman, I would like to spend the few minutes that we have been allotted discussing the tremendous impact the Medicaid Program has had on the lives of so many people with mental retardation.

As legislators, you have a tremendous responsibility in allocating the Nation's financial resources in the most equitable and responsible way. The wisdom of Solomon is being asked of you. With that widsom, we are asking that you look at the Medicaid Program that serves people with mental retardation.

We could speak to you today about significant statistics relative to the Medicaid programs, but authors of Medicaid research—some of whom have been here—have generally not detailed the increased high quality of life that persons receiving title XIX services have realized through the program, and, further, what life would most likely hold for them today without Medicaid.

We believe it would be most beneficial for this subcommittee if I tell you about a few people back home in Maine and how dramatically Medicaid has changed their lives, and what life and ongoing costs would be had Medicaid not touched them through community based programs.

We want you to be profoundly aware that these examples I bring are not isolated stories, are not extreme sagas. Stories like these are being written today in every corner of America where people are being allowed to grow through the support of Medicaid.

We believe that through active individualized treatment in community based settings people "grow and go" through the Medicaid Program.

I have a friend back home in Maine. Her name is Edith. She lived in institutions from age 12 to 47. She is now 54 years old. She has been diagnosed as having severe mental retardation, manic depression, and as being suicidal, self-abusive and assaultive. In 1979, she lived in a $55,000 a year State facility, being isolated, with restraints, being catheterized four times a day, and attempting suicide more often than that.

She told me her main goal in life was to end it. That year I moved her to our $47,000 a year group home against the advice of all clinical staff, but with the support of a Federal court master.

Two and a quarter years later she and I loaded my car with her possessions, and we drove to her new apartment to live with a residential supervisor. When she turned her key to let herself in, she turned off living in a Medicaid home forever.

Six months later she moved to her own apartment, independent of all internal support. Four and a half years from the time that she left the institution, I went to a conference in Minnesota. While I was there Edith called to tell me she had just gotten married.

Yesterday when I left for Washington, her husband put my 40 pound pumpkin in the car and gave me last instructions. In my wildest imagination I never dared dream dreams such as these for persons like my friend, Edith. How much she teaches all of us about our own perceived limitations.

Do you know that at today's cost, through the Medicaid opportunity, if Edith lived until age 70 in that institution it would have cost $2,820,000 to sustain her. As it was, Medicaid spent $132,500 in a Medicaid community ICF/MR, and in doing so saved more than $2.5 million.

Yesterday before I left Bangor I received a call from one of my ICF/MR administrators. He insisted on telling me that it was a day of celebration, and I must come here to you today with this information. At 9 o'clock yesterday, Carla and Donna, two residents with profound mental retardation and autism were, after consistent phase down, taken off all medication. This speaks for the quality of life they have come to enjoy, at a drastic reduction in Medicaid cost, thanks to a drug-free life. Both had been medicated since childhood, one since 18 months of age.

When I first met Carla in a State mental institution in 1979, she was sitting lotus-style in a plastic molded chair in a heavily drug-induced state. She sat there, unmoving, for 6 hours. Now she is drug-free, in a day program, signing and riding on tilt-a-whirls at county fairs, thanks to Medicaid and aggressive active treatment.

Since 1979, 18 persons who had lived in institutions from 8 to 40 years, with a dual diagnosis of mental retardation and mental illness, have come to live in one of our six person ICF/MR and have left that home to live more freely, less expensively and with a better sense of self worth and dignity.

Thank you.

Senator DURENBERGER. Thank you very much.

Mr. Benner?

[The prepared written statement of Ms. Brooks follows:]

National Association of Private Residential Facilities
for the Mentally Retarded

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Area Code 703 / 536-3311

October 6, 1986

The Honorable David F. Durenberger
United States Senate
375 Russell Office Building
Washington, DC 20510

Dear Senator Durenberger:

Thank you for giving us the opportunity to share with the Senate Subcommittee on Health our experiences serving people through the Medicaid program.

Enclosed is a copy of the final five sentences of my prepared oral statement presented to the Subcommittee on September 19th.

I ran out of time mid-way through the first of these sentences. If appropriate, we would like to have them included in the record but, more importantly, we wish to convey their message to you as Chairman of this important subcommittee.

Despite the many problems we and others have identified in the Medicaid program, it has been, and continues to be, the program that is primarily responsible for the movement of people from dependent institutional settings to greater self-dependence in less restrictive environments. Over a period of several years it has demonstrated its cost effectiveness for many others like my friends Edith, Carla and Donna. With the changes recommended by NAPRFMR in the areas of federal look behind surveys, application of the Life Safety Code, regulatory revision, utilization of the Waiver for Home and Community Based Care, and adoption of deemed status for facilities accredited by the Accreditation Council for Services for Mentally Retarded and other Developmentally Disabled Persons, Medicaid could become even more cost effective. Our recommendations would also remove some of the insitutional bias that continues to exist in the program.

States like Minnesota and Maine have demonstrated the difference Medicaid has made in the lives of people with developmental disabilities. This must be encouraged nationwide.

Sincerely,

Bonnie-Jean Brooks
Secretary, NAPRFMR

NAPRFMR WITNESS

Ms. Bonnie-Jean Brooks will testify on behalf of the National Association of Private Residential Facilities for the Mentally Retarded (NAPRFMR). Ms. Brooks is Secretary of NAPRFMR and Executive Director of Opportunity Housing, Inc. in Bangor, Maine. She is also Vice President of the Maine Association of Private Residential Facilities for Persons with Developmental Disabilities.

Ms. Brooks has been appointed by Commissioner Concannon as a representative to the Maine Mental Retardation Federal Impact Council, and she also serves on a Maine Department of Human Services Committee that is rewriting state ICF/MR regulations. In addition, Ms. Brooks has recently served on a HCFA Region I Training Task Force, and she chairs the Northeast Region American Association on Mental Deficiency Division of Private Residential Facilities. She is currently consulting with agencies and individuals in ten states who are unable to find appropriate services for their citizens who are diagnosed as having both mental retardation and mental illness.

Opportunity Housing provides prescriptive individualized residential, day program and other services, directly or indirectly, to persons with developmental disabilities. The persons served are primarily residents of Maine and usually have been diagnosed as having both mental retardation and mental illness. They generally have presented overwhelming behavioral characteristics which have resulted in inadequate placement. Opportunity Housing considers for services only persons for whom no other alternative is available, because their behaviors are considered too difficult to manage by other providers.

Opportunity Housing was incorporated in 1979, as a direct result of the Pineland Consent Decree. During the past seven years, the agency has transitioned 78 persons from institutions for people with mental retardation and mental illness, jails, and more restrictive intermediate care facilities for the mentally retarded to less restrictive residences. Opportunity Housing, Inc. currently operates two ICFs/MR serving six persons each, a respite care home that generally serves four persons at a time, and 25 "specialized projects." The latter are the individualized programs, separately funded for each person (many with the assistance of Title XIX Waivers for Home and Community Based Care), at 15 sites that house one to four residents each. They also have a small developmental day program that serves 18 people for whom they are unable to find alternative day services.

* * * * *

NATIONAL ASSOCIATION OF PRIVATE RESIDENTIAL FACILITIES FOR THE MENTALLY RETARDED

The National Association of Private Residential Facilities for the Mentally Retarded currently represents almost 600 agencies in 48 states and the District of Columbia that together provide residential services to more than 25,500 persons with developmental disabilities. (That is about 20 to 25 percent of the number of persons living in residential facilities managed by the private sector identified in the most recent study.) Our members provide services in a variety of settings. Many operate intermediate care facilities for the mentally retarded (ICFs/MR) and/or residential settings funded in part through the Medicaid Waiver for Home and Community Based Care (HCBC). Virtually all of the persons served utilize Medicaid to cover the costs of physician and hospital services and for other habilitation services such as physical therapy and occupational therapy. Social Security programs — Medicaid, Medicare, Social Services, Supplemental Security Income and Social Security Disability Insurance — are the backbone of the service delivery system for Americans with developmental disabilities.

The cost of lifetime care for these citizens is beyond the reach of most of the families in our nation. State and local government and the private sector rely on Federal programs for financial and regulatory support of people with developmental disabilities. NAPRFMR supports the role of the Federal government in providing for the most basic human needs for adequate food, clothing, shelter, good health, the protection of human rights, and the enhancement of each individual's ability to attain the maximum level of self-dependence possible through therapeutic intervention, education, training and the opportunity for employment.

Without Medicaid, many people would still be living in the dehumanizing conditions that existed in institutions before the program came into existence. Others would have joined the homeless people living on our city streets — some of whom have been identified as being mentally retarded.

Though its medical roots were viewed with suspicion, the Title XIX Medicaid ICF/MR program was welcomed by the developmental disability field as an opportunity to at last develop stable, comprehensive residential programs that would offer not just three meals a day and a place to sleep, but an array of services to enable each individual to become as self-dependent as possible. The ICF/MR program, enhanced by the Section 2176 HCBC Waiver, has fulfilled many expectations, but with modification it could help many more people realize their potential and take their place in our society.

The current status of the Medicaid program is well outlined in the report submitted to Congress by the Department of Health and Human Services in January of this year entitled, "Policies for Improving Services for Mentally Retarded and Other Developmentally Disabled Persons Served Under Title XIX of the Social Security Act." NAPRFMR strongly supports the goal of HHS stated in that document, "to foster the continuing development of strategies emphasizing integration into the community, independence and employment, while still providing support and protection for those persons who need such assistance." We believe that the Medicaid program, in conjunction with the federal legislation cited in the HHS report (i.e.: the Architectural Barriers Act of 1968, the Rehabilitation Act of 1973, the Education for all Handicapped Children Act of 1975, and the Developmental Disabilities Assistance and Bill of Rights Act of 1975) are the key to successful achievement of this shared goal.

As stated in the HHS report, many changes in the treatment of persons with developmental disabilities have occurred over the past two decades. This has been an exciting time for people in the disability field. The availability of funding for educational, habilitation and vocational services has enabled those being served to progress beyond the greatest expectations of families and service providers alike. Active treatment services provided to those residing in ICFs/MR have expanded to meet new expectations for the developmental potential of each resident. Many whose early years were typified by neglect and the absence of programming are achieving new developmental milestones through their participation in comprehensive habilitative programming. The success of young people who have had their disabilities identified at birth or as soon as possible thereafter, and who have been provided with early intervention programs and appropriate developmental services through their school years, have achieved even greater progress. Their potential knows no bounds as technology improves.

Each year NAPRFMR presents an award to an individual with developmental disabilities who has been served by a member agency or home and whose achievements deserve special recognition. Copies of articles describing our Achievement Award recipients from the past three years are attached to this testimony. All of these individuals spent most of their formative years in state institutions. Their disabilities were multiple and of such severity that not even the most optimistic persons could have foreseen how self-dependent each would become. In each case, the Medicaid program provided the means to obtain the training necessary to move to successively less restrictive settings. They are representative of many who have benefitted from the Medicaid program. Ted Rich, thanks to Medicaid, is now self-supporting and even pays for the services he receives in the group home, the place where he chooses to live. Without HCBC Waiver funding, people like Edith Rackliff Brailey and Chuck Reining would not be able to maintain such a high level of independence. Many others will never achieve the level of success these three have reached and will require more intensive support just to maintain their achieved level of functioning.

It is not difficult to understand the popularity of the Medicaid program when such successful outcomes are reached. This success was not achieved overnight. There has been a tremendous increase in the array of services provided since the Medicaid program began. Technology has changed; new techniques have been developed each year which result in greater client growth. This is not achieved without cost, particularly when serving people with more severe disabilities who require a barrier-free environment, health care lifesafety features, and trained staff who are supported by an array of professional personnel. Many of the facilities that were certified as ICFs/MR in the early years of the program did not meet physical plant or program standards, particularly the large state institutions that have been the focus of attention in Congressional hearings that led to the establishment of the ICF/MR program and to the look behind surveys designed to monitor the effectiveness of state ICF/MR survey teams. The general upgrading to meet standards has included extensive physical plant renovations. Such retrofitting will be a one time cost.

Results of some look behind survey decisions, adoption of the 1985 edition of the Life Safety Code without waivers, and some features of the proposed ICF/MR rule changes are expected to lead to future increases in per-client expenditures, some of which may not be necessary. NAPRFMR has identified several features of the Medicaid program which might be modified to improve the cost-effectiveness of the program. Amendments to Medicaid contained in the Consolidated Budget Reconciliation Act of 1985 (COBRA) were designed to address some of the problems. Others are bringing new, unanticipated problems of their own.

I. Look behind survey results:

Senate investigations of deficiencies in federal standards and of abuse that has continued to occur in some large institutions, despite implementation of the ICF/MR program, resulted in federal authority to survey Medicaid certified facilities to "look behind" the work of state surveyors. Federal surveyors are identifying deficiencies that require added expenditures. Most of the deficiencies being cited are clear violations of federal rules and require compliance. Some, however, seem to exceed statutory and regulatory intention and result in expenditure of funds that may be unnecessary.

One outcome of the federal surveys that arouses particular concern is the absence of clear criteria for monitoring active treatment services. NAPRFMR members believe that this concept has been stretched well beyond Congressional intent by some surveyors. To providers active treatment signifies a prescribed program of interventions — generally referred to as an individualized habilitation plan, or IHP — developed according to accepted interdisciplinary team processes to meet individualized needs, which (to paraphrase the Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons) specifies the goals and objectives being pursued by each agency providing services to the individual and the activities being taken to achieve them; identifies a continuum of development, outlining progressive steps and the anticipated developmental outcomes of services.

The activity schedule developed to implement each resident's IHP should follow the normal rhythms of daily life, and although interventions should be applied, as appropriate, in each interaction with the resident; this should occur like good parenting in the form of guidance throughout the day. As in a typical day of school or work, specific times should be set aside for training in the areas identified in the IHP. There should also be time for leisure and recreation, and although some of this should be organized, each individual should be free from formal programming for a portion of each day. This is not to imply that residents should be neglected, but staff intervention should occur as parenting would, in the form of gentle guidance when behaviors indicate that attention is needed. Current federal rules permit periods without formal instruction. This should be retained.

Some NAPRFMR members have been told by Federal surveyors that formal, planned interventions should occur throughout each person's waking hours, seven days a week. Such scheduling violates principles of learning and can be counterproductive when residents rebel against excessive programming. Requirements for continuous programming are costly and inappropriate. They not only escalate costs, but defeat the very purpose they are intended to serve. Each of us needs some time for simple relaxation free from the stress of responsibilities. Persons with developmental disabilities need such time as well. Professionals, who must be presumed to pursue the best interest of their clients; who know the them and have identified their needs and idosyncracies, must be given the flexibility to provide the amount of intervention that in their professional judgement most benefits the client.

Problems are also occurring when survey teams cite deficiencies in an IHP that have not been identified by the interdisciplinary team and for which there is seemingly no evidence of need. While we must assure that residents are receiving accurate assessments and adequate programming, mandating training beyond that identified as needed by a qualified team of professionals is often questionable.

Demands for an increased number of professional staff made by some surveyors frequently seem tied more to some preconceived notion of what should be in place in each ICF/MR than to individual resident needs.

II. Application of the 1985 Life Safety Code:

Although NAPRFMR participated in the development of Chapter 21 of the National Fire Protection Association's Life Safety Code for Board and Care Residential Occupancies, and urged its adoption by the Health Care Financing Administration, we also urged that its use be phased in over a three year period and that waivers be permitted for some specific features added to the requirements by the National Fire Protection Association (NFPA), such as automatic door closures. Our recommendations were rejected by HCFA. Congress should be aware that this will result in immediate expenditures to retrofit small ICFs/MR that are currently meeting earlier editions of the Code. Although these will provide added protection, some mandate more protection than is believed by many to be necessary. The door closures, for example, are appropriate for rooming houses but not for family residences which are the model for most small ICFs/MR. Heating and air ventilation in small residences generally fuction most effectively when doors are open, since return ducts are not placed in all rooms. More expensive automatic door closures attached to the home's alarm system will be required to enable heating and air conditioning systems to function effectively. Our members tell us that automatic door closures of this type range from $250.00 to $490.00 per door.

It is important to remember that no fire-related deaths have been recorded in ICFs/MR or, for that matter, in board and care homes that complied with earlier editions of Life Safety Code requirements for lodging and rooming houses. Those fire deaths that did occur were in homes with serious violations of code requirements.

The original purpose of the special chapter for board and care occupancies was to recognize the presence of staff to assist persons who were less capable of escaping under emergency conditions, and thus enable many in wheelchairs or who require direct supervision to live in home-like settings. Instead, it appears that the new provisions are being applied very conservatively, undermining the intent of those in the field of developmental disabilities to design a flexible system which would obviate the need for sprinklers without requiring people to live in sterile, hospital-like environments.

We hope that with training which will permit and promote less conservative applications of the Code, our original goal can be achieved and it will become a flexible tool that will enable people with disabilities to live in homes like the ones we choose for ourselves and our families.

Despite these initial problems implementing the 1985 Code, it is hoped that the added costs of compliance will be less over time than would be required if all individuals who are nonambulatory or incapable of self-preservation were to be required to live in homes that meet still more strict health care chapters of the Code. The overall cost to Medicaid in providing ICF/MR services to people with severe disabilities should ultimately be less than if the 1985 Code had not been adopted.

Some of the unanticipated problems that are occurring as agencies seek to comply with the stronger fire safety requirements are the result of inappropriate state actions. It is hoped that they will be resolved in the near future. Others, like the requirement for door closures, are within the Code itself. NAPRFMR will be working with the Subcommittee on Board and Care of the National Fire Protection Association to revise Chapter 21 for the 1988 edition of the Code now being drafted. We hope it will offer improvements over the current system, which is just now beginning to provide a record of experience on which to base changes. In the interim, a more gradual phase-in for existing homes and a few waiver provisions would go far to reduce annual costs.

III. Proposed ICF/MR rule changes:

NAPRFMR has long sought modification of the federal ICF/MR regulations which will be responsive to the changes that have occurred in the field since the rules were first published in 1974. The Association strongly supported the principle which guided development of proposed changes to focus more attention on client and staff performance in the active treatment process, following a developmental approach to service delivery. The proposed changes published in the Federal Register on March 4, 1986, are well organized and eliminate repetition of standards that occurs in the current document. NAPRFMR is generally supportive of the added flexibility offered but finds a number of the proposed changes unnecessarily restrictive. Several would increase the costs of services.

The proposed provisions most strongly supported by NAPRFMR include many that will represent a cost savings to the Medicaid program. For example:

o Removal of the requirement that ICFs/MR be required to meet state nursing home safety and sanitation standards will eliminate the requirements still applied in some states that result in the addition of inappropriate and costly features such as drinking fountains in living rooms, sinks and call buttons in bedrooms, and a given number of linear feet between bathrooms and laundry areas and food storage and preparation areas. Some states have even prohibited clients from entering food preparation areas where some of the most important active treatment programming occurs.

o Flexibility provided in proposed rules that pertain to the governing body of an ICF/MR would facilitate practices generally in use in the field today and eliminate the unnecessary administrative requirements for some facilities.

o Proposed elimination of the requirement that the administrator of an ICF/MR be a licensed nursing home administrator or Qualified Mental Retardation Professional (QMRP) is welcomed because it has been an unnecessary and costly standard in many homes serving people with developmental disabilities.

o Liberalization of the requirements for an individual to achieve status as a QMRP is supported for programmatic reasons, but if adopted could also eliminate the need for some ICFs/MR to hire additional, unnecessary staff.

o The proposed use of physician assistants and nurse practitioners to provide physican services, as permitted by state law, is another example of a cost-saving step.

o Increased flexibility in accessing pharmacy services will also represent a cost saving for some ICFs/MR by encouraging the use of community drug stores.

o Permission to use homes that have bedrooms below grade level (if they have a window that is no more than 44 inches from the floor which can be used as a fire escape) would facilitate the conversion of existing homes to small ICFs/MR, thus potentially reducing capital costs.

Provisions which NAPRFMR recommended be modified also include some which have cost ramifications. These include the following:

o Use of the word "continuous" when describing requirements for active treatment in the proposed rules raised concerns similar to those mentioned in the pages 5 - 6 discussion of problems with surveyors who require intrusive intervention with clients throughout the day. If staff were, in fact, required to provide intensive programming every waking hour of every day, costs would escalate significantly, and probably to the detriment of the residents' progress.

- The provision which outlines the services that should be directly provided by each ICF/MR is unclear. If each ICF/MR were required to hire nursing staff rather than contract for these services as necessitated by regulatory and client need, staffing costs would rise considerably for some homes that serve clients who do not require daily medical services.

- The implied inability to lease housing would also result in unnecessary costs if agencies are required to purchase all homes certified as ICFs/MR.

- Proposed rules that would require such things as awake staff on duty for any client who requires a medical care plan are often unnecessary and, of course, costly. Staffing requirements should always be tied to residents' needs.

- Although physician services would be modified if the proposed rules are adopted, they are still more excessive than needed for people who do not have other than routine health care needs. Most people with mental retardation and related conditions who live in an ICF/MR require habilitative rather than medical services. They are not ill and do not require 24 hour nursing supervision. Requirement for all professional involvement should be tied to client needs. This includes the mandate for their participation in interdisciplinary team (IDT) meetings, a costly requirement for professionals like physicians who are highly paid and seldom donate their time, particularly where they feel it is not needed. The decision to attend IDT meetings should ultimately be their own.

- The appearance of a proposal that all mattresses used in ICFs/MR be "fire safe" was met with consternation. This goes well beyond the already strict requirements established by the National Fire Protection Association. NAPRFMR understands that fire-safe mattresses are generally required only in prisons, and that they are uncomfortable and expensive.

In commenting on the proposed rule changes, NAPRFMR supported some recommendations that may add to the cost of the program. Of particular concern is the unavailibility of funding in some states to cover the cost of services or equipment required by Medicaid rules. These include such things as dental care, eyeglasses, prostheses, special chairs, and even personal clothing and other necessary equipment. These are not frivolous items, but necessities that should be reimbursed through Medicaid in all states. The provision of these is mandated by ICF/MR rules. The failure of some states to reimburse such items is inexcusable and is a violation of the Section 102(a)(13)(E) "Boren Amendment" requirement that states provide reimbursement which will enable "economically operated facilities.... to provide care and services in conformity with applicable State and Federal laws, regulations, and quality and safety standards." The federal government should require more than "assurances" that state plans meet applicable laws and regulations. State Medicaid Plans should be reviewed for compliance with the law and none should be approved if they fail to provide reimbursement for those things required.

Although data that accurately compare the costs of services in large state-operated institutions with that in privately-operated programs is difficult to obtain, the reimbursement of services in the state institutions nationwide is generally higher than that for the private sector. These differences become greater in many states following passage of the Section 102(a)(B)(E) amendment, which eliminated the requirement that facilities participating in the Medicaid program be reimbursed on a "reasonable cost-related basis." Regulations promulgated to implement that amendment also significantly reduced Federal review of State Medicaid Plans, encouraging greater disparities in state reimbursement systems. As a result, it is increasingly difficult for the private providers to cover the costs of services, creating a disincentive to deinstitutionalization. Care should be taken to assure that state reimbursement systems do not inhibit the movement from state institutions to community based living arrangements.

IV. Waiver for Home and Community Based Care:

Though limited in scope, the Section 2176 Home and Community Based Care (HCBC) Waiver enables providers to serve people in smaller community settings who would otherwise be living in an ICF/MR, ICF general, skilled nursing facility or hospital. It is used when community services are the preferred and most effective option. For all but a few, the overall cost of services is less, and costs are spread over more funding sources, including SSI to pay the cost of housing when people are not served in their family home. Several provisions of COBRA were designed to facilitate use of the Waiver. More can be done, however, to enable people to move more readily from institutional environments to small community settings.

If the HCBC Waiver formula were not so restrictive, it could be used more effectively to prevent institutionalization. This could forestall the certification of new ICFs/MR which may well be developed in many states as those young adults who have remained at home and attended public school programs require alternative residential placement. As pointed out in the January 1986 HHS report to Congress, over the last two decades the increase in federal support has enabled many families to keep children with severe disabilities at home that in past years would have been placed in institutions. As these children reach young adulthood, they are no longer eligible for educational programs and there are few day programs available to take their place. This puts stress on families who are suddenly faced with having 24-hour responsibility for their dependent who is disabled. In addition, these families are aging and will not be able to maintain their dependents at home indefinitely. Every state is facing the prospect of having to find appropriate housing and services for this population. The Medicaid program is a logical resource. It should be designed to promote services in the least intrusive manner possible.

The fact that the Waiver is not permanent greatly inhibits its use by states that fear termination of funding for people who have become accustomed to being supported in community settings. Many private providers also hesitate to begin serving people when they know the funding source may cease at a future date. The burden of telling people that funds no longer exist to serve them falls on the provider, not on the government entity that terminated the program.

NAPRFMR recommends that the Waiver be given permanent status as an optional program available to states under Medicaid. Encouraging the provision of respite care under the Waiver would also enable families to delay the out-of-home placement of people who are disabled.

V. Provisions of COBRA which move the Medicaid program in more positive directions:

NAPRFMR strongly supported Medicaid amendments included in COBRA which required HCFA to publish regulations adopting the 1985 edition of the Life Safety Code in all ICFs/MR, and the more comprehensive proposed ICF/MR rule changes. We would like to take this opportunity to thank the members of this Committee who supported those amendments.

NAPRFMR also supported the amendments that: enable states to obtain an automatic one-year renewal of their waiver, extend the waiver renewal period from three to five years; permit the coverage of optional case management services; permit the replacement of waiver recipients who die or become ineligible for services; allow higher income maintenance standards; cover respiratory-dependent recipients; prohibit mandatory cost savings when people are served under the HCBC Waiver rather than in a Medicaid certified facility; and prohibit a regulatory cap on federal financial participation. Some of these clearly have a price tag attached.

An additional COBRA amendment supported by NAPRFMR is the provision that added flexibility and will improve services provided under Medicaid by enabling states that so choose to permanently reduce the number of beds in state institutions which are found to have deficiencies that are not life-threatening. This will prevent the necessity of spending huge sums of money on facilities that are scheduled to be phased down. If not hampered by overly restrictive regulations, this provision will enable people to move to more suitable environments that will encourage growth.

Yet another COBRA provision that will improve the delivery of services to people with developmental disabilities is the inclusion of a definition of habilitation services within the HCBC Waiver program. We have urged HCFA to adopt the same definition more broadly within ICF/MR regulations to assure that each individual will receive the full range of services necessary to reach their full potential. A legislative mandate may be required before the Administration will apply the definition to all Medicaid programs.

VI. Deemed status for facilities accredited by national voluntary accrediting bodies:

Standards published by the Accreditation Council for Services for Mentally Retarded and other Developmentally Disabled Persons (AC MRDD) in 1971 provided the basis for Federal ICF/MR standards in 1974. AC MRDD standards have been modified several times since then and were relied upon extensively for the recently published proposed ICF/MR rule changes. In the Supplementary Information that accompanied the proposed rules, HCFA stated, "In revising these standards, we have based our proposals primarily on the accreditation standards published in 1983 by the [AC MRDD], particularly in the Active Treatment Services section of our proposed standards." A side-by-side comparison of current draft AC MRDD standards with proposed ICF/MR regulations reveals close similarities. AC MRDD, in fact, has far more standards devoted to client advocacy, active treatment, and the humane and ethical monitoring of intervention techniques, which we feel are predictive of good services.

NAPRFMR supports inclusion of a provision in Federal law which would enable nationally recognized accrediting bodies with comparable standards to establish formal agreements with the Department of Health and Human Services for the purpose of declaring accredited facilities certified as ICFs/MR. Medicare law currently allows the Secretary of HHS to deem certification of a facility if it is determined that a national accrediting body provides reasonable assurance that the Medicare requirements are met as a consequence of such accreditation. Medicaid statute has no provision comparable to Section 1865(a) of the Social Security Act for Medicare facilities.

The deeming of accredited facilities would reduce Medicaid costs by eliminating duplicative surveys. We understand that AC MRDD surveys are also far more cost-effective than are state Medicaid surveys. Both use professional staff, but AC MRDD uses fewer for each survey and completes its examination in fewer days. The effectiveness of AC MRDD's sampling method is thought to be at least partly responsible for the difference.

The Federal look behind process could be used with accredited facilities, as it currently is with those certified by State Medicaid agencies, to monitor the effectiveness of voluntary accreditation.

Summary of NAPRFMR Recommendations

The following statements summarize the NAPRFMR recommendations contained in this document:

- o NAPRFMR is questioning the decisions of some look behind survey teams who are citing deficiencies that exceed the requirements of federal regulations. These should be discontinued.
- o HCFA adoption of the 1985 edition of the NFPA Life Safety Code without waivers or a phase in period recommended by NAPRFMR will result in immediate cost increases in the Medicaid program. Some of the features which might be waived, most specifically automatic door closures, are not only costly but are perceived by many to be inappropriate and unnecessarily restrictive in home-like settings.
- o Many of the proposed rule changes for ICFs/MR will result in a cost savings to Medicaid, others recommended by NAPRFMR could increase

the savings without diminishing the effectiveness of the program. Specific recommendations appear in the body of the testimony.

- The Federal government must assure that State Medicaid reimbursement systems cover the costs of services and equipment mandated by Federal regulations.
- Care should also be taken to assure that state reimbursement systems do not inhibit the movement from state institutions to community based living arrangements.
- The Section 2176 HCBC Waiver should be given permanent status as an optional program available to states under Medicaid, and the formula should be modified to prevent institutionalization, just as it now promotes deinstitutionalization.
- Respite services should be encouraged under the HCBC Waiver program to help families maintain their dependents with disabilities at home, thus delaying or preventing out-of-home placement.
- Federal regulations to implement provisions of COBRA must not be so restrictive that they impede the intention of Congress to provide flexibility in the Medicaid program. Specific concerns are cited in the testimony.
- Deemed status should be provided in the Medicaid program as an option for facilities accredited by HHS approved national voluntary accrediting bodies whose standards are comparable to ICF/MR rules.
- NAPRFMR strongly recommends the continuing role of Medicaid in supporting programs for people with mental retardation and related conditions that enable them to fulfill their potential and take their place in society.

Conclusion

There is a growing body of documented evidence that demonstrates the cost-effectiveness of well managed private residential and supportive programs. This is accomplished despite the differences in reimbursement between publicly and privately operated programs found in most states.

Our newsletter articles provide excellent examples of the important role Medicaid has played in enhancing human development and reducing individual reliance on government support.

The problems we have identified in this testimony are not offered to provide recommendations concerning elaborate revisions in this complex program, though we believe comprehensive changes in Medicaid could be beneficial. What we have tried to do is to identify trends we as service providers are confronting which seem to be diminishing the cost-effectiveness of Medicaid. As providers who are responsible for human lives 24 hours a day, 365 days a year, our focus is often on the present. The conflicting demands we face today are placing quality services in jeopardy. On the one hand, the regulations are becoming more demanding, and on the other we are expected to reduce costs. The two are not compatible.

We respectfully request your careful consideration of our testimony in your deliberations over ways to improve the Medicaid program. NAPRFMR and our members will be available at any time if we can be of assistance to you and other Senate Finance Committee Members.

Thank you for your attention.

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NATIONAL ASSOCIATION OF SUPERINTENDENTS OF PUBLIC RESIDENTIAL FACILITIES FOR THE MENTALLY RETARDED

September 6, 1986

TITLE XIX AND PUBLIC INSTITUTIONS FOR THE MENTALLY RETARDED

The availability of federal support to public residential facilities (PRFs) for persons who are mentally retarded has been highly instrumental to and, in many cases, the primary reason for the tremendous improvements in the quality of services currently provided.

First, Title XIX funds enabled states to increase staffing levels significantly. In 1965, for example, the staff:resident ratio was approximately 1:2; in 1981, it was 2.11:1 (Scheerenberger, 1965, 1981). Not only was the number of staff increased, but also the diversity of their training and experience. With improved salaries and working conditions, the turnover rate was reduced appreciably. It was not uncommon in the sixties for as many as 80% to over 100% of the staff to turn over annually. By 1980, that figure had dropped to less than 20% (Scheerenberger and Jones, 1981). This stability, in turn, rendered training and experience more meaningful, with a subsequent improvement in resident programming. Without federal funds, these gains would have never been realized.

Second, the issuance of regulations and "standards," combined with both state and federal surveys, produced both attitudinal and environmental changes which resulted in the elimination of unwarranted dehumanizing practices and the introduction of principles associated with the developmental model and normalization.

The fact that these changes have occurred is attested to by the recent series of federal "look-behind" surveys which generally concluded that, in all but a few instances, PRF services, while not always what one would completely hope for, were far from being as insidious as many had proposed.

It is fully recognized that the federal government, as well as most state governments, is confronted with a serious fiscal situation. Yet, it is imperative that continued federal participation be assured, especially since many PRFs receive more than 50% of their funds through Title XIX. If these monies were reduced, it undoubtedly would adversely affect services and programs since, in all probability, the states would not substantially increase their contributions. In fact, many states have already begun to cut positions solely for budgetary reasons (Scheerenberger, 1982).

Further, reductions in federal funding to PRFs might well prove equally disastrous to community programming. Most states have a firm statutory obligation to its institutional programs. The same is often not true for community efforts. Thus, if PRFs became seriously fiscally troubled, a state may decide to redirect its community support back to the institution. This, indeed, would be unfortunate.

Deinstitutionalization is at the crossroads. In the early days of Title XIX, many states, in order to participate in the program, placed many people into what, in essence, were alternative institutional settings, such as nursing and county homes. Over the years, approximately 50% of persons discharged from PRFS went to such settings. Also, to avert admissions to a PRF, these same resources were used (Scheerenberger, 1981, 1982, 1985). Thus, as both federal and state governments have come to realize, tens of thousands of mentally retarded people living in such inappropriate settings need to be relocated into more community-based, home-like environments. Combining this situation with the fact that over 90,000 developmentally disabled persons are graduating from high school each year, many of whom should be living away from home, developing an adequate number of group homes with the prerequisite support services and vocational opportunities presents a problem of considerable magnitude.

It is also evident that the existing population in the Nation's PRFS consists primarily of adult, multiply handicapped, severely and profoundly mentally retarded persons, many of whom present serious behavioral problems (Scheerenberger,1985). These individuals are going to be extremely difficult to place in an alternative non-institutional community setting.

In brief, the Association recognizes and appreciates the invaluable assistance of the federal government over the past dozen years and urgently requests its continuation in the interest of both residential and community programming. Also, it is not the intent of the Association through this statement to discourage, in any way, the continued advancement and promotion of sound community programming. In fact, it reconfirms its 1974 position: "The National Association of Superintendents of Public Residential Facilities for the Mentally Retarded fully supports efforts toward deinstitutionalization, institutional reform, and acceptance of a changing role (National...,1974, p. 3).
Respectfully submitted

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STATEMENT OF PETER BENNER, EXECUTIVE DIRECTOR, COUNCIL 6, AMERICAN FEDERATION OF STATE, COUNTY, AND MUNICIPAL EMPLOYEES, ST. PAUL, MN

Mr. BENNER. Thank you, Senator.

My name is Peter Benner. I am executive director of AFSCME Council 6. We represent 18,000 employees in the State of Minnesota, State and university workers, among whom are approximately 4,000 employees at the State regional centers, State hospitals.

Our union nationally represents over 100,000 workers who care for ICF/MR residents. You have our statement which we would like to have included in the record. I will not go over that in detail other than to summarize a number of our recommendations, and then I would like to deal with what we have been doing in Minnesota with the regional centers.

We believe that a general review of the ICF/MR regulations should be undertaken to determine the applicability of the current standards. Arbitrary regulations should be eliminated. The regulations which remain should be well defined and consistent.

Alternatives to the ICF/MR Program should retain the valuable existing resources and standards. We believe one of the most valuable current resources are the skill and experience of the workers now caring for the retarded in the State and other ICF/MR facilities.

Finally, in terms of recommendations for the future, we believe that all parties need to be involved and participate in a change to the future.

In Minnesota, our State institutions have been under consent decree now for almost 10 years. Very great changes happened in those 10 years: many fewer residents, many more staff, costs for that entire time have continued to go up for reasons that have already been described.

We are at a stage now where closure of the institutions one at a time is the probable next step. The politics at the State level of dealing with a change to the future start to get very difficult, very tense, when there starts to be losers. We now have caps on community ICF/MR beds; private sector providers also are being encouraged to decertify beds.

For much of the last 10 years our union and our members in Minnesota I think have been seen as part of the problem by many advocates of change. It was said that our members worked in the institutions, and therefore were incapable of caring for recipients of our services and had behavior traits and characteristics that somehow should not be allowed to find their way into the new system. We obviously disagreed with that. Our members disagree with that strongly.

Both we, the members of the executive branch and members of the legislature, and members of advocacy groups, have been trying to find common ground to move in a new direction, and that has been a very difficult set of discussions, I think internally within each of our organizations and between our different organizations.

One thing we are now doing—and we are doing this with a combination of waiver money and funding from the Federal Mediation and Conciliation Service for labor management grants, labor management cooperation—is to get into the business of providing State-run community facilities that are less than ICF/MR level of care. Our first home opened just within the last week outside of Therabough, MI, and what we are hopeful that this will do is provide a common direction for the future which meets the needs of parents who would like to see their relatives moved out of the institution. It meets the needs of our members, which allows them to continue to provide care, and helps deal with some of the double funding problems that have already been discussed here today.

I would be more than willing to get into this more after the red light ends. Thank you.

Senator DURENBERGER. Thank you very much.

[The prepared written statement of Mr. Benner follows:]

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Good afternoon, my name is Pete Benner. I am Executive Director of Council 6 of the American Federation of State, County and Municipal Employees, covering Minnesota's state workers.

I speak on behalf of 4,000 Minnesota institutional and community-based workers. Overall, AFSCME represents 100,000 workers who care for ICF/MR recipients.

In the past five years increasing scrutiny has been directed toward federal Medicaid expenditures for our nation's developmentally disabled population. Legislators and federal administrators, seeking ways to counteract the burgeoning federal budget deficit, have begun examining federal domestic initiatives program-by-program. Many activists in the mental retardation/developmental disability field, disgruntled with the disproportionate share of Medicaid funding directed towards large ICF/MR institutions, have sought ways to retain funding levels while shifting expenditures away from institutional settings into community-based systems. At the same time, parents and relatives of residents have sought a stable environment for their relative regardless of setting. This hearing represents an attempt to examine the background of the debate surrounding the Medicaid ICF/MR program.

My home state of Minnesota has participated extensively in the ICF/MR program. In Minnesota alone over 1,000 individuals receive care in large public institutions, while over 5,000 residents reside in private community-based ICF/MR facilities. Though Minnesota has used the ICF/MR program more than any other state to develop community-based facilities, very few severely disabled individuals have been moved to private sector ICF/MRs. Eighty-five percent of those individuals remaining in the state's regional centers are severely or profoundly disabled.

Currently, through the use of a Federal Mediation and Conciliation Service grant, our union and the States of Wisconsin and Minnesota are attempting to use labor-management cooperation to imporve state provided care for the developmentally disabled in institutional and community-based settings. I will discuss this state-operated continuum of service later.

in the public service

ICF/MR Costs

There is no question a dramatic growth in ICF/MR expenditures has occurred over the past decade. Few, if any individuals involved in the day-to-day care of developmentally disabled individuals though would consider those expenditures an unwise investment.

It is important to examine why the Medicaid ICF/MR program appears to be an easy target for budget cutters.

First, there is no hiding the rapid growth in ICF/MR expenditures over the past decade. As Senator Packwood has noted, in 1976 the Medicaid ICF/MR program served 89,000 persons at a total cost of $635 million. In 1985 $4.7 billion was spent providing care and services for 146,000 developmentally disabled persons. Second, many critics of the ICF/MR program argue that funding is inequitably distributed. For example, in 1980, approximately 150,000, or 6% of those with mental retardation nationwide, received ICF/MR services.

Other detractors cite the ICF/MR program as the most costly component of Medicaid: with ICF/MR recipients constituting only .7% of the total number of Medicaid recipients, but simultaneously representing 12% of the total cost of Medicaid. On the surface these statistics would argue for reform of the ICF/MR program. A cursory view of aggregate data, though, leaves one with little insight into what the ICF/MR program is actually providing in 1986.

ICF/MR Benefits

To fully understand cost allocations in the Medicaid ICF/MR program, one must examine service recipients and services received. Moreover, a historical perspective should be added to this analysis by comparing these factors in their present form to the same elements a decade ago.

Today, roughly 146,000 individuals receive care and services under the ICF/MR program. The vast majority of these individuals are severely or profoundly disabled. Compared to the total population of mentally retarded individuals, 50% of whom are moderately to profoundly disabled, over 80% of individuals who are ICF/MR beneficiaries and who are residing in public sector institutions are severely or profoundly disabled.

The proportion of institutionalized residents who are profoundly retarded has increased steadily from 15% in 1939 to 57% in 1982. The number of profoundly retarded individuals' who were institutionalized actually increased from 51,000 in 1965 to

68,000 in 1982.(1) Colorado predicts a 15% rise in this population alone by 1995.(2) Thus, the argument can be made that public institutions have become primarily dedicated to the care of profoundly retarded people.

Cost of care for the medically fragile and profoundly disabled is significantly higher than for groups with lesser disabilities regardless of setting. Thus, the changing resident characteristics have contributed to higher costs over time. While fewer developmentally disabled persons received ICF/MR services ten years ago, the percentage of mildly and moderately disabled Medicaid recipients was higher.

Some argue that closure of large public institutions will greatly reduce ICF/MR costs. This argument completely overlooks the characteristics of current institutional residents. Moreover, this argument is not supported by academic studies. Very few studies document lower cost for community settings compared with institutional facilities. The federal home and community-based waiver program, which permits states to provide home and community-based care if costs are lower than those in institutional settings, has been opposed by the Reagan adiminstration because experience nationwide reveals it has been more costly to provide services in the community.(3)

Comparative studies showing community-based care to be cheaper than institutional care either compared groups with different disability levels or different levels of service provided. Studies in California, Washington and Florida concluded that community placements are no less costly than institutional care when all required services are provided and that significant cost "savings" only appear when specialized services are not provided, are unavailable or are underutilized.(4)

The current body of research documenting cost studies of care for the mentally retarded, according to the most recent survey commissioned by the Federal government, cannot substantiate claims that either institutional care or community-based care is consistently less expensive. If a cost advantage exists in the community, concludes the survey, it is due in large measure to low effective wage rates.(5)

Moreover, as the most severely disabled individuals move from institutional to community facilities, the overall cost of care will rise. In part, this cost expansion is due to the loss of economies of scale found in congregate living facilities. Staffing, medical, transportation and supply costs may all rise because of this organizational disaggregation. Without effective federal oversight, cost cutting by entrepreneurs may harm quality care in the community.

In the past decade, behavioral research, technological innovations, and changing ICF/MR program expectations have led to higher Medicaid costs. At the time of the ICF/MR provision enactment in 1971, cost was a secondary factor to Congress. What was uppermost in the minds of Congresspersons was meeting the unmet needs of mentally retarded individuals residing in public institutions. Thus, the ICF/MR program was designed as an incentive to induce state reform. According to one authoritative source:

> Unlike the ICF-general, the ICF/MR program was not conceptualized as a means to a cost savings, but instead as a means to expand Medicaid coverage to a specific population whose general quality of care was an increasing well publicized national scandal.(6)

Creation of the ICF/MR program went beyond simply providing an alternative to nursing home care. Unlike the SNF and ICF enabling legislation, the ICF/MR language required the provision of "active treatment" in order to qualify for federal financial participation. While ill defined in statute and committee reports, active treatment has remained a key criterion distinguishing the ICF/MR program from its nursing home counterparts. Besides the active treatment requirement, ICF/MR regulations raised quality care standards in public institutions to levels previously believed unattainable. Though the development of active treatment has been hampered by lack of funding for staffing and staff training, recent efforts have led to marked improvements in treatment delivery.

Compliance with the full ICF/MR regulations was not mandatory until 1977 and in the case of some provisions until 1982. Following enactment of the new standards, physical plant and staffing costs esclated rapidly to meet the impending regulations. For example, in 1976, Wrentham State Hospital in Massachusetts had 2,200 residents and 700 staff. Today, Wrentham has 700 residents and 2,400 staff members.(7) While staffing and related costs have grown dramatically at Wrentham over the past decade, active treatment is possible whereas in 1976 serious understaffing problems negated any opportunity for quality care.

Despite the threat of Medicaid funding disallowances, the introduction of active treatment has developed slowly in some facilities. Lack of a clear definition of active treatment, the reluctance of federal administrators to conduct look-behind surveys, and apparent state ICF/MR compliance led to a chaotic monitoring process and continual substandard care. In essence, the physical features of the human warehouses of the past were dramatically improved but treatment and habilitation lagged behind capital improvements in some facilities.

Since a series of Congressional hearings in 1984, the Health Care Financing Administration has added staff and has conducted an enormous number of audits and look behind surveys. These actions have led to tense federal-state negotiations and to Medicaid disallowances, but at the same time in many instances residents in institutional settings are now receiving better care. This emphasis on individual care, as outlined in the 1985 HCFA rule and regulations regarding active treatment, has greatly benefitted residents but has simultaneously added substantial additional costs to the ICF/MR program.

Review Process

To understand the problems inherent in the survey process and the costs involved, let me describe the process whereby a typical institution is reviewed by federal investigators. Since most, if not all, large public institutions have been surveyed in the past several years it is possible to analyze patterns found in these surveys.

In 1985, a National Association of Superintendents of Public Residential Facilities for the Mentally Retarded (NASPRFMR) study of look-behind surveys in 73 facilities revealed that Federal surveys consistently found a lack of active treatment, and inadequate participation of professional staff and inadequate development of behavior programs.(8) State surveyors also typically found institutions lacking active treatment programs but, unlike federal surveyors, found nursing and dietary concerns as the second and third most cited deficiencies. Thus, while most evaluators agree active treatment is uniformly missing in most institutional settings, there is little agreement on other deficiencies and considerable disagreement concerning how to remedy active treatment deficiencies.

On the surface it would appear all parties involved in ICF/MR compliance proceedings are working towards the same goals, namely improved quality care for residents. How to achieve that end generates considerable debate. In our experience, federal surveyors have received a mandate, be it a cost-conscious or a quality care mandate, to conduct serious surveys and disallow funds where applicable. Unfortunately, the renewed focus began without a designated active treatment definition, protocol or uniform application. As late as the summer of 1985, surveyors did not use any protocal for surveys in 17 of 73 institutions.(9) Despite initial setbacks, exhaustive federal surveys have been completed for most public residential facilities.

While most state mental retardation officials and state legislatures ultimately cooperate to achieve compliance, these same state policymakers are examining limited funding sources as closely as are federal legislators. Increases in developmental center appropriations may limit road building or advances in public education. Thus, in many instances, a subtle process of brinksmanship occurs where parents, advocates and worker representatives shuttle between the two parties attempting to produce an acceptable resolution.

Furthermore, because of budgetary constraints, states for some time have been trying to close large costly institutions. The pace of this phasedown has markedly slowed as resident characteristics have changed. Moreover, methods of developing and monitoring privatized community-based facilities for profoundly disabled individuals have not been as easy to develop as those for mild and moderately disabled persons.

Faced with multiple active treatment deficiencies and assorted Qualified Mental Retardation Professional and direct care staff utilization citations, most state administrators must immediately add considerable staff at all levels, must develop a viable active treatment plan and must demonstrate that such changes are permanent. In our experience facilities have had to add from 100 to 300 FTEs to comply with current active treatment regulations. In numerous proceedings, in Iowa, Kansas, Wisconsin to name a few, our union has chosen to actively participate in the survey process, either requesting specific interpretations from federal surveyors or consulting outside active treatment specialists who assist the state in developing correction plans. In Iowa, for example, AFSCME was confronted with a state administration reluctant to increase staffing at one developmental center with serious active treatment deficiencies. Our union became actively involved in the survey process and successfully lobbied the Iowa legislatiure for additional staffing positions which ultimately met Federal regulations.

We believe surveys should be uniform from jurisdiction to jurisdiction. The development of well defined, consistant standards that are not arbitrary should be continued. Moreover, all parties, including workers, should have input in the survey process.

ICF/MR Program Alternatives

A number of plans to reform the ICF/MR program have been discussed over the past five years. State mental retardation administrators have recommended capping the overall allotment of federal ICF/MR dollars in exchange for drastic changes in ICF/MR regulations and for greater state program flexibility. The

Medicaid 2176 Waiver program was an attempt to both contain costs and bypass the need for institutional placement. The results of the waiver program have not been totally conclusive. Very little client level information comparing waiver recipients to institutional ICF/MR recipients has been forthcoming.

The Community and Family Living Amendments (CFLA) supported by the Association for Retarded Citizens and championed by Senator Chafee of Rhode Island was initially designed to rapidly close public institutions and shift Medicaid ICF/MR funding to community facilities. Supporters of the legislation highlighted tremendous cost savings accruing to the ICF/MR program based on the block grant method of funding. Evidence for such cost containment has never been documented and subsequent revisions of the CFLAs have downplayed the predicted cost savings of the legislation. The amendments would also allow states to draft their own regulations, permitting tremendous variations between states. The lack of uniform standards would create an extremely chaotic survey process.

The COBRA provision allowing alternative ICF/MR plans of correction to be submitted to HHS when non-threatening deficiencies are found, is, like the CFLAs, a deinstitutionalization plan without much concern for community support built into the outcome. Evidence from around the country indicates many community systems face their own serious deficiencies.(10) Thus, reductions in ICF/MR funding may prevent both development of quality community-based service delivery systems as well as complete development of active treatment programs in existing facilities.

AFSCME Reform Efforts

Any alternatives to current ICF/MR legislation should retain the valuable existing resources and standards. These resources include the skills and experience of workers. Moreover, any future regulatory flexibility should be built on a strong base of uniform regulations that guarantee quality care across all jurisdictions.

In order to increase the number of developmentally disabled persons who can live in the community and in order to maintain quality care, our union has promoted for more than a decade the development of state-operated community-based facilities. For some individuals, institutions remain the least restrictive environment. For other severely disabled persons, discrimination by private sector vendors has left no opportunity for community-based living. By April, 1986, thirteen states had developed some form of state-operated community residences for mentally retarded persons. Colorado, Connecticut, Massachusetts, New York and

Rhode Island are committed to extensive state-operated community-based facility systems. Sixty percent of all new community facilities for the mentally retarded in Massachusetts will be state-operated.

Rhode Island has recently announced plans to close its developmental center by 1991. If completed on schedule, Rhode Island would be the first state in the country without a large public ICF/MR institution. The progress in Rhode Island has in large part stemmed from an historic agreement signed in 1979 between AFSCME, Council 94 and the State of Rhode Island emphasizing the least restrictive environment for residents and transfers without layoffs for workers. All parties in Rhode Island have worked closely to develop one of the best community service delivery systems in the country.

State-operated community facility programs permit access to care, accountability and continuity of care. In general, greater state monitoring, higher staffing ratios and lower worker turnover allow a level of quality of care for the most vulnerable segement of our population.

In my home state Minnesota, and in Wisconsin, through the use of FMCS funded labor-management committees, we are engaged in labor-management planning for the development of state-operated community facilities. In Minnesota several state-operated community facilities will open in the next several months. Severely disabled residents currently living in state institutions will move along with state workers currently employed in these facilities to the newly created community homes. A state-operated continuum of care system, from institutional to community settings and beyond, is not necessarily a cost containment measure but at a minimum accountability and continuity of care are insured.

Our union has conducted numerous seminars for membership around the country explaining and interpreting active treatment. Moreover, we have employed and consulted with numerous active treatment specialists to assist both individual facilities and state administrators in the development of new policies and procedures.

Last, the International staff and Council staff from around the country have actively participated in review proceedings. Our members are dedicated to the provision of active treatment for the mentally retarded. As a union we intend to campaign for the resources needed to guarantee quality care.

* * * * *

Limiting or reducing Medicaid ICF/MR funding will only produce disastrous results for present and future Medicaid recipients. As has been mentioned, in some states the number of severely and profoundly disabled individuals will rise in the future. These individuals must be guaranteed appropriate care and habilitation. Now, more than ever, residents are receiving the care they need thanks to uniform federal enforcement. If states or the private sector are unwilling or unable to care for the most severely disabled, then the federal government should continue to provide that care through the ICF/MR program. Certainly, the survey process can be greatly refined to guarantee uniform outcomes. If abrbitrary standards exist, they should be eliminated. States should be induced to develop quality continuums of care. Before greater regulatory flexibility inducements are allowed, though, we must insure existing regulations are well defined and consistant. Only from this foundation can uniform quality care be developed.

We must not repeat the problems encountered in the nursing home ICF industry. For years chain nursing homes operators have emphasized Medicaid reimbursement rates over quality care. For years scandals have rocked that industry. Entrepreneurs and chain operators are now seeking to penetrate the fledging industry of care for the mentally retarded. The ICF/MR program was originally designed to make up for the shortcomings of various states and to shield resident care from unscrupulous vendors. We must insure future ICF/MR funding will preserve these goals.

Senator **Durenberger**. Let me defer to my colleague from Rhode Island, Senator Chafee.

Senator **Chafee**. Thank you, Mr. Chairman.

Mr. Benner, I would make one correction if I might on your testimony on page 11 toward the bottom of the page. You are referring to the community and family living amendment supported by the ARC and championed by Senator Chafee in Rhode Island. And then you say, "Supporters of the legislation highlighted tremendous cost savings accruing to the ICF/MR Program based on the block grant method of funding."

I would demur there. No one, neither I nor any of those who have been pressing the CFLA Program, the amendments, have highlighted cost savings. We have suggested that possibly that is true. It might well be a fringe benefit, as I have mentioned here in my remarks, but that was never the driving force of the CFLA.

The driving force for it was that we strongly believe that an individual reaches his or her greater potential in a community-based setting. The costs have not been highlighted. And maybe there are more; we think there are less. But that is not a highlight of the program.

Secondly, I would like to refer to what you say on page 13, which is absolutely true, that Rhode Island is moving ahead, and we have had an excellent relationship, our State administrators, with the AFSCME, the State employees. And, indeed, we do have State-run facilities and it has worked out very, very successfully, emphasizing, as you say, the least restrictive environment for the residents.

So that has been an extremely happy facility, a happy arrangement, and it has succeeded because not only has the State and the people been dedicated—there has been very careful preparation—but the State employees have cooperated.

So I want to express to you, and through you to our State employees who are members of your association, my gratitude for that.

Mr. **Benner**. Thank you, Senator.

Senator **Chafee**. Thank you.

I want to thank the other witnesses too.

Dr. Scheerenberger. I would like to add one comment. I meant to and then forgot to.

In this planning as we go along, I hope we will revise our thinking about the parents. There have been a goodly number of parents who have taken—and I see no one is speaking to represent them—that have taken a tremendous amount of personal and social abuse in their feelings about what is in the best interest to their youngsters. And I hope we don't lose sight of the parents and their feelings in all of this, and that they will, in fact, be a genuine partner in whatever decisions are being made.

Thank you.

Senator **Durenberger**. Thank you.

George, do you have any questions?

Senator **Mitchell**. Mr. Chairman, I would just like to ask Miss Brooks, in your written testimony you advocate making the Medicaid 2176 waiver permanent. In Maine, has this waiver been beneficial to the delivery of services to the developmentally disabled, and how would a permanent waiver help to improve the delivery of services?

Ms. BROOKS. It would help by cutting down on the amount of time, bureaucracy and frustration that it takes to regularly renew the waiver. Maine has just gone through a very difficult period of time where it thought that due to the COBRA provision, it would be able to renew its existing waiver, but found that it could not do that, and it put resource development on hold for a lot of people ready to move out of the institution because the Federal Government found problems with that waiver. We are now in a 1-year extension. If it were a permanent waiver, we would have just gone on providing services.

Senator MITCHELL. Do you believe there is a role for large institutions in the treatment of the developmentally disabled or do you think that large facilities should be phased out entirely?

Ms. BROOKS. I have to remove myself from representing my national association and comment to you as a provider from the State of Maine.

I don't think there is a role. I go to Pineland frequently, and I have not met a person at Pineland who I believe cannot be served in the community.

Senator MITCHELL. Thank you, Miss Brooks.

Senator DURENBERGER. I thank all of the witnesses for your testimony and your patience with this long hearing. I appreciate that a lot.

Our next panel is composed of Ruth Luckasson, the chairperson of the Legislative and Social Issues Committee of the American Association on Mental Deficiency, from Albuquerque; and Dr. Colleen Wieck, the executive director of the Minnesota Governor's Planning Council on Developmental Disabilities, from St. Paul, and she is also Chair of the Public Policy Committee of the National Association of Developmental Disabilities Councils.

Senator CHAFEE. Was there a chartered plane that came from Minnesota today? [Laughter.]

Senator DURENBERGER. Bargain rates from Northwest. We only have one airline now.

Senator CHAFEE. Who is home tending the store?

Senator DURENBERGER. Ruth, I guess you were introduced first. We welcome you here today. And your statement is part of the record. You may proceed to summarize it.

STATEMENT OF RUTH LUCKASSON, CHAIRPERSON, LEGAL AND SOCIAL ISSUES COMMITTEE, AMERICAN ASSOCIATION ON MENTAL DEFICIENCY, ALBUQUERQUE, NM

Ms. LUCKASSON. Thank you very much for the opportunity to appear before you today.

The American Association on Mental Deficiency is the oldest and largest interdisciplinary organization of professionals who work exclusively in the field of mental retardation. The total membership is almost 10,000 professionals nationwide. These professionals are organized into a number of divisions, including such examples as administration, legal process, medicine, nursing, recreation, occupational therapy, et cetera. The Association does reflect the broad perspectives of diverse disciplines concerned with the problems of mental retardation. The Association annually prepares legislative goals in order to identify issues and positions important to the lives of individuals with mental retardation.

The Association is committed to supporting the highest standard of services, training and research in the field of mental retardation. This longstanding commitment leads us to support the creation of appropriate community living arrangements and supportive services that will enhance the lives of disabled individuals and allow them to participate with other citizens in their home communities.

Recognizing the human dignity and potential of all individuals with mental retardation, one of the stated goals of the Association in its constitution is "to promote the development of appropriate community based services for people with mental retardation."

The great successes that Congress initiated in creating equal educational opportunities for children with handicaps should not be frustrated by now denying adult opportunities to those same children. These children are graduating from excellent public education programs with the skills, or the preliminary skills, for community participation and rich lives, and they are discovering a residential service system left over from the days when handicapped people were denied full citizenship, removed from their families and placed in isolated institutions for an entire lifetime without any sort of educational opportunities at all.

The history, by the way, has been described by Justice Stevens as "grotesque."

The skills and independence that these children and their families worked so hard to gain in school, and the faith and trust of their families that handicapped children were no longer going to be excluded from participation as citizens, require that the adult service system respond to the real needs of citizens.

I urge that States be given more funding flexibility as they create and maintain living arrangements and service systems for people with mental retardation.

I suggest that the title XIX Waiver Program is not adequate for all of the reasons that you have heard today. And in addition, I would like to suggest that the enlightened State administrators that you have had testifying before you today do not represent the larger number of State administrators.

I also urge that the Federal Government not abandon its critical role in protecting the lives of individuals with disabilities. It is imperative that the Federal Government establish and enforce program standards and periodic review to assure that disabled individuals have access to habilitation and residential services that are consistent with the standards of the profession.

Independent monitoring systems that will protect the rights and dignity of vulnerable disabled people are also essential. And the Federal Government must assure that citizens with mental retardation are provided due process protection as they are admitted, transferred, and discharged from residential programs.

A study recently completed in New Mexico suggests that those very provisions for monitoring and review must anticipate and accommodate appropriate movement of clients as they progress to less restrictive settings between community facilities.

The American Association on Mental Deficiency is strongly committed to a more appropriate system of Federal funding for mental retardation services, and we stand ready to be of assistance as we can.

Thank you.

[The prepared written statement of Ms. Luckasson follows:]

HEARING BEFORE THE SENATE FINANCE COMMITTEE
SUBCOMMITTEE ON HEALTH
WASHINGTON, D.C.
September 19, 1986

Ruth Luckasson
Chair, Legal and Social Issues Committee
American Association on Mental Deficiency

Thank you for the opportunity to appear before you today and to testify on this crucial issue of how the Medicaid program can more adequately respond to the needs of individuals with mental retardation. I am Ruth Luckasson, an attorney and Associate Professor of Special Education at the University of New Mexico. I am the Coordinator of Mental Retardation Programs at the University. I served as co-counsel for a consortium of disability professional organizations in Amicus Curiae briefs before the United States Supreme Court in the recent cases of Bowen v. American Hospital Association (the Baby Doe case), 106 S.Ct. 2101 (1986), and City of Cleburne v. Cleburne Living Center (discriminatory zoning against people with disabilities), 105 S. Ct. 3249 (1986). I am also the Chair of the Legal and Social Issues Committee of the American Association on Mental Deficiency (AAMD) and I am testifying today in that capacity. I request permission to submit for the record the 1986 Legislative

Goals document of the American Association on Mental Deficiency as well as the Association's 1984 position paper on community living for individuals with mental retardation.

The American Association on Mental Deficiency is the oldest and largest interdisciplinary organization of professionals who work exclusively in the field of mental retardation. The total membership of almost 10,000 professionals nationwide is organized into divisions and subdivisions in the following areas: Administration; Communication Disorders; Education; General; Legal Process; Medicine; Nursing; Occupational and Physical Therapy; Private Residential Facilities; Psychology; Religion; Resident Living; Social Work; Vocational Rehabilitation; Nutrition and Dietetics; Recreation; and Community Living. The Association thus reflects the broad perspectives of diverse disciplines concerned with the problems of mental retardation. The Association prepares legislative goals each year in order to identify issues and positions important to the lives of individuals with mental retardation, and engages in other activities such as Amicus Curiae briefs and public education in order to improve the understanding of public officials and the general public of the needs of people with mental disabilities.

The Association is committed to supporting the highest standard of services, training and research in the field of mental retardation. This longstanding commitment leads us to support the creation of appropriate community living arrangements and supportive services that will enhance the lives of disabled individuals and allow them to participate with other citizens in their home communities. Recognizing the human dignity and potential of all individuals with mental retardation, one of the stated goals of the Association in its constitution is "to promote the development of appropriate community based services for people with mental retardation" (AAMD Constitution, art. II g.).

The two principal accomplishments in the field of mental retardation in the last two decades are universal educability (as reflected in the Education for All Handicapped Children Act of 1975) and a recognition that the provision of residential and other services should occur in more normalizing environments and consistent with the least restrictive environment principal (as reflected in the Developmentally Disabled Assistance and Bill of Rights Act of 1975). When it passed the the Education for All Handicapped Children Act (EAHCA), Congress found that the special education needs of handicapped children were not being met, that the children did not have equality of opportunity, that families were being forced to find services outside of the public schools often at great distance from the family home and at their own expense, that the state and local agencies could not fulfill their responsibilities without additional resources, and that it was "in the national interest that the Federal Government assist State and local efforts to provide programs to meet the educational needs of handicapped children in order to assure equal protection of the law" (Public Law 94-142, 20 U.S.C. section 1400).

In the Developmentally Disabled Assistance and Bill of Rights Act, Congress found "(1) Persons with developmental disabilities have a right to appropriate treatment, services, and habilitation for such disabilities" and "(2) The treatment, services, and habilitation for a person with developmental disabilities should be designed to maximize the developmental potential of the person and should be provided in the setting that is least restrictive of the person's personal liberty" (42 U.S.C. section 6010). Congress has recognized these community living rights on the one hand, but the federal government has impeded their implementation on the other hand by leaving in place a funding mechanism that promotes unnecessary institutionalization.

The great successes that Congress initiated in creating equal educational opportunities for children with handicaps should not be frustrated by denying adult opportunities to these same children. These children are now graduating from excellent public education programs with the skills for community participation and rich lives, and discovering a residential service system left over from the days when handicapped people were denied full citizenship, removed from their families and placed in isolated institutions for an entire lifetime (for a description of the history of discrimination against people with mental retardation, a history Justice Stevens described as "grotesque", see Ellis and Luckasson 1986a). The skills and independence that these children and their families worked so hard to gain in school, and the faith and trust of their families that handicapped children were no longer going to be excluded from participation as citizens, require that the adult service system respond to the real needs of citizens with mental retardation.

Unnecessary and debilitating institutionalization must end. Congress has recognized this. Researchers, scholars, families, and the disabled individuals themselves have recognized the potential of disabled individuals to live and work in the community, near family and friends. However, the funding mechanisms necessary to implement proper living arrangements have not only lagged behind, but have actually sustained an outdated model of service delivery, at great cost both financially and in terms of harm to disabled citizens.

The federal government has an important role in assuring high quality, adequately funded services and environments for all individals with mental retardation, regardless of age. The manner in which the federal government exercises that role will largely determine where mentally retarded people live, what the quality of their environments will be, what services they receive, and whether they have opportunities to develop their potential.

To date, federal funding policy has promoted and supported unnecessary institutionalization of disabled people. Under Medicaid, large amounts of money have been available to remove persons with mental retardation from their homes and communities and place them in isolated large facilities, but only very small amounts have been available for support to families so that they can assist the person in their homes or for other services which could prevent or postpone out-of-home placement. While some flexibility has been available under the so-called waiver program, it has been inadequate -- the waiver program is a "waiver" from the program's primary direction and operating presumptions in favor of institutionalization. It is critically flawed in that it is time-limited, subject to the reluctance of some state bureaucrats to challenge outmoded but entrenched institutions, granted solely at the discretion of the Secretary, and insufficiently stable to create the trust needed by families and disabled individuals as they make plans for their futures.

Over the last decade members of our organization as well as other professionals in the field have gained a great deal of experience in creating and operating community services for persons with mental retardation. Most of these efforts have been funded in an ad hoc manner at the state and local level. These efforts have been studied by social scientists (see especially the work of Braddock), and we now have a voluminous literature on the ability of disabled individuals to live successfully in the community and the ability of professionals to create and operate community services. I draw your attention to the Pennhurst Longitudinal Study by Conroy and Bradley and the detailed recommendations found at the end of the study.

But one of the questions remaining has been whether individuals with mental retardation could continue to grow and learn after they were placed in a community living system. Two colleagues and I have recently had occasion to study almost 300 individuals who live in group homes of varying levels of restriction in Albuquerque, New Mexico. One of the questions we were interested in was the extent to which these individuals' residential and service needs would change even after they reached a group home. (Traditionally, merely reaching the group home has been regarded as a successful placement.) We investigated whether individuals moved "up the ladder" to less restrictive placements and "down the ladder" to more restrictive placements during their time in a community service system. We calculated the movement rates of individuals who have mental retardation as they moved from more restrictive settings to less restrictive settings within a community service system. Our data showed that over a three year period, an average of 23% of the residents moved each year to less restrictive living arrangements including independent apartments. Our data showed an average of 4% of the residents moved down the ladder to more restrictive placements, including back to the institution. For our purposes today, I believe that the important point is that people with mental retardation can grow and learn over time and that their service needs and preferences can change over time. Funding mechanisms must recognize, anticipate and even encourage this flexibility.

I urge that states be given more funding flexibility as they create and maintain living arrangements and service systems for people with mental retardation. But I also urge that the federal government not abandon its critical role in protecting the lives of individuals with disabilities. It is imperative that the federal government establish and enforce program standards and periodic review to assure that disabled individuals have access to habilitation and residential services that are consistent with the standards of the profession. Independent monitoring systems that will protect the rights and dignity of vulnerable disabled people are also essential. And the federal government must assure that citizens with mental retardation are provided due process protections as they are admitted, transferred and discharged from residential programs.

Our study suggests that these provisions for monitoring and review must anticipate and accomodate appropriate movement of clients between community facilities.

The American Association on Mental Deficiency is strongly committed to a more appropriate system of federal funding for mental retardation services and we stand ready to be of assistance to the Congress in any way we can as Congress seeks to address this most urgent problem in the lives of citizens with mental retardation.

REFERENCES

Braddock, D. (1986a). From Roosevelt to Reagan: Federal spending for mental retardation and developmental disabilities. American Journal of Mental Deficiency, 90, 479-489.

Braddock, D. (1986b). Federal assistance for mental retardation and developmental disabilities: A review through 1961. Mental Retardation, 24, 175-182.

Braddock, D. (1986c). Federal assistance for mental retardation and developmental disabilities II: The modern era. Mental Retardation, 24, 209-218.

Conroy, J.W. & Bradley, V.J. (1985). The Pennhurst Longitudinal Study: A report of five years of research and analysis. Philadelphia: Temple University Developmental Disabilities Center. Boston: Human Services Research Institute.

Ellis, J.W. & Luckasson, R. (1986a). Amicus curiae brief of AAMD et al. in City of Cleburne v. Cleburne Living Center (U.S. Supreme Court docket no. 84-468).

Ellis, J.W. & Luckasson, R. (1986b). Discrimination against people with mental retardation: A comment on the Cleburne decision. Mental Retardation, 23, 249-252.

Ellis, J.W. & Luckasson, R. (1986c). Denying treatment to infants with handicaps: A comment on Bowen v. American Hospital Association. Mental Retardation, 24, 237-240.

Senator **Durenberger**. Thank you very much.

Coleen, it is just great to have you here today. And I don't mind the fact that there are a lot of Minnesotans here. I am proud of all of you.

STATEMENT OF COLLEEN WIECK, PH.D., EXECUTIVE DIRECTOR, MINNESOTA GOVERNOR'S PLANNING COUNCIL ON DEVELOPMENTAL DISABILITIES, ST. PAUL, MN; VICE PRESIDENT AND CHAIR, PUBLIC POLICY COMMITTEE, NATIONAL ASSOCIATION OF DEVELOPMENTAL DISABILITIES COUNCILS

Dr. **Wieck**. Thank you, Mr. Chairman, and members of the committee. My name is Colleen Wieck, and on behalf of all the State developmental disabilities councils, we appreciate the opportunity to testify on needed changes in the Medicaid Program.

Developmental disabilities councils are in a particularly strategic position to understand the impact of Medicaid on the lives of people with developmental disabilities. Our councils are composed of both consumers of services as well as the government officials responsible for providing services. We understand both the problems and the potential of Medicaid.

My testimony is divided into four sections critical to analyzing the impact of Medicaid on people with developmental disabilities.

First, billions of dollars are spent on Medicaid services for people with developmental disabilities, but what are the outcomes? Medicaid may in fact be fostering retarding environments and inactive treatment. There is no doubt that Medicaid has greatly improved services for people with developmental disabilities through enriched staffing and more program resources. However, there are serious deficiencies that more money simply cannot fix.

Whether the source of information has been the university research that we have heard, the State and licensing certification reports, the HCFA look behind audits, the ACMR-DD reports, or Lowell Weicker's report on conditions in institutions, there is a single thread that runs through all of these reports, and that is at the individual level, what does the person need and what is the person actually receiving?

If you look closely, Medicaid may in fact be funding dependency rather than independence. It may foster inactivity rather than productivity. It may keep people segregated rather than encouraging integration in community life. Restructuring is necessary to address these consequences.

Second, Medicaid is a powerful incentive for out-of-home placements. For those families who have kept their children with developmental disabilities at home, they quickly realize that government provides services if the child or adult leaves home. Services to support families and children always finish last when compared to funding for institutions and group homes.

Over half of the States are provided family support programs because the States recognize you have to support the families first, but Medicaid funds services to supplant families.

We do have the Medicaid home and community based waiver program, but that is very limited, and it has flexibility but it does not really restructure Medicaid.

Earlier when the administration witnesses spoke, they talked about the number of people who were profoundly and severely handicapped living in institutions. Let me remind you that in Minnesota we have 15,000 children who are labeled mentally retarded in our special education classes. We only have 31 of those children living in State institutions. We only have a few hundred of those children living in community ICF/MR facilities. The next generation will not be living in segregated sites. We are already demonstrating that people with the most profound handicaps can live in the community.

Third, restructuring Medicaid means facing the tough issues, making inevitable choices, and enduring some political heat.

Large Medicaid funded residential services are being down-sized. Continued reductions are inevitable, and as a result, we have to face the tough issues, and that is employee dislocation, what to do with vacant buildings and land, what to do about economic impact, how to structure a public process, and how best to serve people with mental retardation and developmental disabilities.

In Minnesota, we have undertaken a study to address these issues. We do have policy papers that can be used by other States. We do have to praise Pete Benner and the AFSCME union for bringing the need into the legislature and allowing us to face the tough issues.

Fourth and finally, restructuring Medicaid really means catching the new waves. This is an opportunity to fund both what is needed and what is possible. Innovation is occurring right now throughout the United States. We are beginning to talk about real homes, and that means existing housing units, and making accommodations to those units. Real jobs, as David Mank mentioned, in the regular workplace, and real friends, not paid care givers. We are talking about the real community, not phoney service systems that perpetuate clienthood.

Included in my testimony are 10 features of a Medicaid funded service system and 10 characteristics of a reformed service system. The Citizen's League in Minnesota in 1983 really brought these points out in their report on residential care. And, again, let me underline, we are trying to strive for truly individualized services. We need to ask parents and individuals, what do they need? What do they want? I think the criteria in the future should be age appropriateness—in other words, would you or I do something similar to these activities. Let me assure you that there is a lot of peg boards and a lot of stacking rings that we would not be dealing with as adults.

I want to inform you about the functional nature of tasks. In other words, if the person weren't doing it would someone else who is paid be doing that, and also the opportunities for interaction with people who aren't paid care givers in the regular community setting.

Thank you.

[The prepared written statement of Dr. Wieck follows:]

TESTIMONY SUBMITTED
BEFORE THE
SENATE FINANCE COMMITTEE

SUBMITTED BY
THE NATIONAL ASSOCIATION OF
DEVELOPMENTAL DISABILITIES COUNCILS

COLLEEN WIECK, PH.D.
VICE PRESIDENT NADDC
CHAIRPERSON NADDC PUBLIC POLICY COMMITTEE
EXECUTIVE DIRECTOR, MINNESOTA GOVERNOR'S PLANNING
COUNCIL ON DEVELOPMENTAL DISABILITIES

September 19, 1986

Developmental Disabilities Councils across the country are in a particularly strategic position to understand the impact the Medicaid program has on the millions of Americans with developmental disabilities. Their role as planners and advocates brings them into daily contact with the problems and potentials of Medicaid.

NADDC appreciates the opportunity to discuss the impact the Medicaid program has on people with developmental disabilities and to suggest ways to restructure the program to meet the real needs.

I. BILLIONS OF DOLLARS ARE SPENT, BUT WHAT ARE THE OUTCOMES? MEDICAID MAY FOSTER "RETARDING ENVIRONMENTS" AND "INACTIVE TREATMENT"

We know a great deal from the research literature about the differences between institutional and community-oriented care for people with developmental disabilities. Medicaid tends to fund and upgrade institutional care.

Despite the investment of billions of dollars in such facilities, studies unanimously conclude that community care is more humane, results in startling improvements for individuals, is more closely aligned with Constitutional principles and is more cost effective than institutional care.

The damaging effects of institutionalization on people with developmental disabilities are well documented. Institutional conditions have led to lawsuits in several states including Minnesota (Blatt, 1973; Blatt and Kaplan, 1966; Flint 1966; Goffman, 1966; Halderson v. Pennhurst, 1977; and Taylor, 1977.) In a 1977 accreditation survey of 48 state mental retardation facilities, 35 failed the test of minimal treatment quality, failing for the following reasons: (a) excessive use of chemical restraint and physical seclusion; (b) the impersonal nature of the physical environment; (c) excessive crowding in living spaces; (d) failure to provide comprehensive, interdisciplinary initial and periodic evaluation, program planning and follow-up and lack of developmental services; (e) lack of use of direct care personnel in training residents in self-help skills; and (f) failure to employ sufficient numbers of qualified personnel in direct care, medical, social, therapeutic, psychological and vocational training services. (Braddock, 1977) In April of 1986,the Senate Subcommittee on the Handicapped released a 250 page report showing that times have changed very little since the above findings and, in fact, some of the institutions visited were reminiscent of the appalling conditions of the 1950's and 1960's.

A number of studies have reported positive attitudes toward community living on the part of deinstitutionalized persons and their parents. The vast majority of individuals expressed satisfaction with their placements in contrast to their feelings about institutional life. (Scheerenberger and Felsenthal, 1977; Edgerton 1967; Edgerton and Bercovici, 1976; Aninger and Bolinsky, 1977; McDevitt, Smith, Schmidt and Rosen, 1978; and Birenbaum and Seiffer, 1976).

The third major body of research attempts to differentiate between various types of institutional and community facilities and to identify the factors responsible for changes in residents' behavior and progress. Overall, the attributes which have been found to produce gains in adaptive behavior and general developmental growth are MORE LIKELY to prevail in smaller community facilities. Attributes include: individualized attention (Baroff, 1980); resident-oriented care practices (Balla, 1976; Baroff, 1980; King, Raynes and Tizard, 1971; and McCormick, Balla and Zigler, 1975); existence of personal effects, privacy in bathrooms and bedrooms (Balla, 1976 and Baroff 1980); community exposure and social interaction (Crawford, 1979 and Baroff, 1980); and experienced, trained direct care staff (Dellinger and Shope, 1978 and Baroff, 1980.)

There should be no doubt that smaller, home-like settings are preferable to large congregate ones in the face of such evidence.

II. MEDICAID IS A POWERFUL INCENTIVE FOR OUT-OF-HOME PLACEMENTS

For those people with developmental disabilities who have never been in an institution, we discover another major and cruel effect of Medicaid. Faced with inadequate resources and community supports, families are presented with powerful incentives to send their children away in order to receive Medicaid reimbursed services. Compared to the billions spent on out-of-home placements, less than 1% of the funding is designated for family support services.

There have been several studies on the effects on families when they have children with disabilities with respect to family structure (Fotheringham & Creal, 1974; Beckman-Bell, 1981; Paul & Porter, 1981; Willer & Intagliata, 1984; McCubbin, Joy, Cauble, Comeau, Patterson & Needle, 1980; Turnbull, Summers & Brotherson, in press); stress (Wikler, 1981; Shapiro, 1983) and coping (Wright, 1970; McDaniel, 1969; Neff aned Weiss, 1965). According to several investigators (Gruppo, 1978, Minde, Hackett, Killon & Sliver, 1972; Heisler, 1972), families of children with disabilities go through stages similar to the reaction to death. Despite improvements in services over the last 50 years, the major family problems have not changed (Farber, 1979).

Other research notes that services which support the family and child in the natural home have finished last when compared to other deinstitutionalization services (Loop and Hitzing, 1980). Disabilities create financial hardships for families because of costs for adaptive equipment, medication, therapies and lost income due to care-giving responsibilities. Family subsidies can be of great help in meeting these costs (Turnbull and Turnbull, in press; Patterson and McCubbin, 1983; Boggs, 1979; Moroney, 1981). Traditionally, however, in large measure due to the Medicaid program, resources become available once the handicapped child leaves home (Horejsi, 1979), substituting for, rather than supplementing the family (Moroney, 1979).

In reviewing the policy biases regarding supporting and not supplanting the family, one of the largest concerns is that policy makers are torn between the desire to provide for needy persons and the fear of creating uncontrolled programs. Policy makers are faced with questions of eligibility; whether to relate benefits to the characteristics of the family or to the level of functioning of the child with a disability; how to coordinate subsidies with tax policy; how to coordinate with other income maintenance programs; how to balance the competing demands for funds from state institutions and well-established community programs. In addition, providing stable family support occurs in the unstable context of society where there are dozens of political, economic, social, cultural, technological, psychological and demographic variables affecting living arrangements.

In spite of these barriers, however, more than half of the states have adopted family support programs. Research supports what we see as the obvious benefits of family support: development at home is better (Poznanski, 1973); a family provides social development and emotional security (Schield, 1976); children with disabilities have a right to be a member of a family (Vitello, 1976); and habilitative family care includes care, training and supervision in a planful manner (Horejsi, 1979).

The rising cost of residential placements has intensified the search for alternatives to out-of-home placements and a "rediscovery" of the family. While some argue that by focusing on cost, attention is shifted from civil rights and humanitarian concerns, the economics cannot be dismissed. While the states are struggling to find ways to provide family support services, Medicaid continues to offer only family supplantation services.

It should be mentioned here that the Medicaid Home and Community Based Care Waiver is an excellent approach which has begun to address the need to support rather than supplant families. However, the services under the waiver need to be dramatically increased and eligibility expanded. Expanding the waiver should be viewed as a stop-gap approach and policy makers should bite the bullet and solve the larger structural problams and totally eliminate the institutional bias of the Medicaid program.

III. RESTRUCTURING MEDICAID MEANS TOUGH ISSUES, INEVITABLE CHOICES AND POLITICAL HEAT

Downsizing of large facilities, whether they are institutions or community residential facilities, is inevitable.

The basic issues remain the same: what to do with buildings; what to do with employees; how to mitigate the economic impact of the change; how to involve the citizens of local communities in a public process; and how to implement the solutions. I hope to present some answers on how to approach these issues.

During the 1984 Legislative Session, the Minnesota DD Council of the State Planning Agency was given lead responsibility to conduct a study and propose a plan for state hospitals precipitated by (1) the sudden closure of Rochester State Hospital, (2) the Title XIX Home and Community Based Waiver which called for additional reductions in the mental retardation units, (3) the Welsch v. Levine Consent Decree, and (4) the proposed reorganization of the state hospital system by the Department of Human Services. Eight reports answered specific questions posed by the legislation. The study that we conducted involved all stakeholders and resulted in legislative action. I have brought copies of the executive summary of these reports for the committee.

The first priority in planning must be the individuals who are served, and the states must undertake independent verification of individualized needs and services to meet their needs. Other issues also need attention, such as economic impact, employee displacement, and alternative use of buildings. I offer the following suggestions based on Minnesota's experience as you consider ways to restructure the Medicaid program and address the tough issues.

A. Alternative Uses of Buildings

Alternative uses of buildings must receive attention. One option for those in disrepair is to declare them surplus property. Our analysis shows that many states do not excel at disposing of surplus property. Generally speaking, state agencies report that they do not save money by using state hospitals for other government uses, due in large part to the condition and age of the buildings, energy and renovation costs.

Of the 31 institutions reported closed nationwide, none has been purchased by private industry. Over half have been converted to other types of institutions, e.g., corrections, veterans, geriatric apartments, colleges and religious organizations.

States should have a systemwide capital improvement planning process that recognizes long-term space requirements and the condition of the buildings. Remodeling should be avoided if the buildings are destined for closure. States should declare such buildings as surplus property, and demolish, if necessary, any buildings in poor condition.

States should develop an aggressive, coordinated marketing strategy for all potential alternative uses of large facilities. Specific decisions will require the active involvement of state, county and local agencies, and affected communities. States should ease any constraints on the sale of state property to the private sector.

B. Impact on Public Employees and Local Communities

A critical area to focus on is the employees of institutions. Most legislative bodies are very concerned about the effects on the employees should a state facility close. States should gather information about the projected displacement of state employees because of deinstitutionalization, and the extent to which displacement can be mitigated through attrition, retirement, retraining, and transfer. The state should also survey state facility employees to determine future career choices.

Institutional closure can significantly affect a community's economy. The smaller the community and less diverse its commercial or industrial base, the greater the impact of any closure or downsizing. Economic impact is not only a function of where employees live and spend their money but also where they work in terms of commuting distance.

For purposes of Minnesota's report, there are three economic impact areas: 1) the primary impact zone is where 50% of the employees live; 2) the secondary impact zone is where 75% of the employees live (including the primary impact zone); and 3) the regional impact area is where at least 90% of the employees live and includes both primary and secondary zones.

We looked at the direct effect of hospital employment (employment as a percentage of total area employment; payroll as a percentage of total area wage and salary income; and estimates of unemployment by county); indirect employment loss; state hospital purchases; effect of resident/patient spending; and effect of visitor spending.

States should develop alternative economic development strategies which require a cooperative effort between state and local officials. Economic impact zones may be one way to handle this issue in the future.

C. Public Opinion and Citizen Input

Public opinion and citizen concerns must be heard and a process developed to elicit them. Some strategies are: 1) holding town meetings in each affected area; 2) soliciting letters from the public and interested parties; 3) establishing an 800 phone number for a call-in day; and 4) distributing monthly bulletins on progress to announce meetings to interested individuals and organizations.

States must anticipate and plan for the economic chain reaction characterized by direct loss of institutional jobs, indirect loss of jobs because of slowed industrial growth, lowered gross community income, reduced retail sales, closed stores, fewer families, underutilized schools, increased taxes, higher utility costs, depressed housing market, and rising unemployment.

States must develop a process for public involvement during closure or reallocation of resources to prevent these factors from being barriers to implementing a deinstitutionalization policy.

D. Balancing the Cost Factors

In general, fifteen (15) years ago, the care given in institutions was custodial, and the cost per day was extremely low. Court cases and federal standards resulted in better staffing. Costs increased. During this time, people with developmental disabilities were moving to the community but costs continued to increase in institutions because: 1) the fixed costs were higher due to fewer residents; 2) remodeling and construction occurred across the United States to meet federal ICF-MR standards; 3) staffing increased or stayed level in order to reach ratios; 4) unionization of public employees occurred which led to higher salaries; 5) inflation had an impact; 6) the proportion of residents with severe/profound mental retardation increased as people with lesser handicaps left; and 7) indirect costs were added such as overhead and other state administrative costs in order to maximize federal financial participation.

During this same period the number of group homes in the community increased dramatically, the ownership patterns ranging from family, nonprofit, profit, chains, or systems. Family operations are the least expensive. Community residential facilities now serve all ages and all types of handicaps but the proportion who are most dependent is slightly lower than institutions.

Average per diems should not be compared between institutions and community facilities because costs vary by type of resident (age, level of independence, services needed, and staffing needed). Children are always more expensive than adults. People with more severe handicaps are more costly regardless of setting. Per diems do not contain the same items. No standard chart of accounts or cost accounting system exists. There are several ways of determining costs which produce different outcomes in cost studies.

Some other important conclusions from past cost comparison studies are: 1) costs do not differ if both types of clients are truly provided the full array of needed services; 2) by adding in day programs and medical services, the difference narrows; 3) we need to add in the issue of "family" that provides care: the family may be the most cost-beneficial approach; and 4) reallocation of funds must be considered if numbers of people keep moving out of institutions.

The Pennhurst study concluded that: 1) state salaries and fringes are higher than community salaries and fringes; 2) community staff spend more hours of direct staff time per client than Pennhurst staff; 3) there is a greater division of labor in state hospitals--more management, more specialists, and more medically oriented staff (community staff do more jobs); 4) savings in community are due to use of generic services; 5) how long will we expect a low paid, transient work force to serve people with more severe handicaps in the community? 6) rather than say community services are cheaper, we should say that we get more staff time for the money; and 7) some institution programs are less expensive than community; most institutions are more expensive; average per diem reflects a wide range of people.

E. Options and Recommendations

There are four options presented in Minnesota's report. They may be seen as steps in a plan toward closure or as discreet decisions.

1) Keep all state hospitals/institutions open but downsize them.
2) Decentralize the state hospitals and begin state-operated, community-based services.
3) Increase efficiency and introduce elements of competition in all state hospitals/institutions.
4) Close one or more state hospitals/institutions.

The first option, downsizing, has effects on employees. Critical areas to plan for include: (1) projecting the number and types of staff reductions; (2) emphasizing natural attrition rather than lay-offs as a first option; (3) making early retirement attractive; and (4) adding medical insurance benefits for people until they reach age 65 years. This option is also less expensive than layoffs.

Downsizing also has effects on buildings and energy use. The demand for living space goes down, yet capital costs will continue for remodeling/renovation. If the residents can consolidate living space, then selected buildings can be declared surplus and sold, rented, or demolished.

The second option, decentralizing the state hospitals/institutions, could involve looking at Rhode Island's approach in beginning state-operated, community-based services. In Minnesota, the American Federation of State, County and Municipal Employees and the Department of Human Services prepared proposals to follow this option.

Decentralization has effects on residents and employees. Individuals continue to move to the community. Employees can bid on positions in community settings and can be covered under collective bargaining and pension plans. Retraining would be necessary. Space needs would be reduced. Property can be declared surplus. The state might incur new capital costs in the community or existing housing could be used. Economic impact can be dispersed depending on relocation of residents.

The third option, improving the efficiency and effectiveness of state hospitals and introducing elements of competition, includes having: 1) management information systems in place; 2) state hospitals generate revenue as a function of services rendered; 3) each state hospital be responsible for program mix, budgeting, marketing, and rate setting; 4) no catchment areas; and 5) counties and case managers be responsible for payment of service.

Improved efficiency has the following effects: 1) Individuals and counties would have choice of using state hospitals at a prenegotiated cost of service; 2) State hospitals would still be under the same policies; 3) There would be more need for flexibility than civil service currently allows. Employees would be trained and transferred based on need. 4) Each state hospital would have control over buildings. There would be an incentive to conserve; 5) Proceeds of sale of property would revert to state hospitals; 6) Rental value would approach fair market value; 7) Per diems would reflect true costs.

States need to be cautious about using this approach. There is concern about "dumping" most difficult clients ("creaming") or not providing service. Minnesota has up to this point not rejected clients. True competition may not be possible dependent upon each state's rate setting mechanism. Counties may have differing capacities to handle these new responsibilities.

The final option, closure of institutions, while it ultimately should be the goal, is extremely difficult to do as a first step since there is little political or financial incentive to close them. Terminations are usually accompanied by a budget crisis and/or an ideological struggle. There is a lack of systematic evaluation studies to determine impact of closures. Closure usually does not occur because instant opposition is galvanized and the forces of incrementalism encourage most programs to grow rather than be terminated. States should first hypothetically close their institutions and assess and plan for the impacts as was done in Minnesota.

IV. RESTRUCTURING MEDICAID MEANS CATCHING THE NEW WAVES AND FUNDING WHAT IS POSSIBLE

The essential changes needed in Medicaid can readily be seen when one contrasts what currently exists and what should exist in serving people with developmental disabilities given the innovations that are fast becoming "state of the art." There are at least ten features of the present system which, if reversed, would solve many of the fundamental problems faced by people with developmental disabilities.

WHAT IS	WHAT SHOULD BE
1) Most dollars are tied to institutions such as state institutions and ICFs-MR	1) Most dollars are tied to to individuals.
2) Funding sources dictate where people live, consequently, many live in state hospitals or ICF-MR facilities with few prospects for living in less restrictive settings.	2) Individuals or guardians dictate where they live. People may leave these facilities if they choose.
3) Reimbursement mechanisms tend to discourage deinstitutionalization or independent living.	3) Reimbursement mechanisms promote deinstitutionalization and independent living.
4) Reimbursement mechanisms encourage families to place children with developmental disabilities in residential facilities.	4) Reimbursement mechanisms are flexible enough to allow families to care for their children at home.
5) There are no incentives to use less restrictive, less costly options. As a result, taxpayers pay more.	5) Incentives exist to use least restrictive, lower cost options. Taxpayers pay less for better service.
6) State maintains duplicative, two-tiered system of state institutions and community facilities.	6) Affords the opportunity to reduce capacity of the state institution system and the community residential system.
7) Virtually no screening mechanisms are in place.	7) Screening mechanisms are in place.
8) The reimbursement system is open-ended, fee for service. Few incentives for high quality providers.	8) The reimbursement system is limited, prospective. Some funding tied to provider performance.
9) People have no incentives to use high quality, low-cost, preferred providers.	9) People have incentives to use preferred providers.
10) People have few service options within the group home setting.	10) People have new choices such as contracting out or owning a share of the home.

A. Catching the New Waves

Innovative developments in services are currently occurring throughout the United States and federal policy should encourage and support their spread in areas such as citizen owned housing and supported employment.

In Brookline, Massachusetts, twenty-two units of condominium housing have been developed for adults with developmental disabilities. The units are integrated into the community and allow ownership of living space, friendship, and support of trained staff.

In the area of employment, individuals with mental or physical limitations have much to contribute to society. Many have the ability to perform valuable functions for employers. But, these individuals need challenging jobs, appropriate and adequate training, and consideration of their limitations in the job matching and training process.

For many individuals, the major limitations have not been disabling conditions. Instead, they have been the stereotypes, expectations, and attitudes of individuals who do not have disabilities. These prejudices have resulted in individuals with disabilities being excluded from the experiences they need to qualify for and obtain jobs. They have also been victimized by a rigid model that has not kept pace with a changing society.

Throughout the country, new careers are being developed for individuals with disabilities, and technology is being applied to compensate for physical and mental limitations. These new approaches should be nurtured. However, there are far too many places where the old traditional models are being used and not working. Consumers, advocates, agencies, and employers are seeking more successful models.

The traditional vocational model, a continuum that requires an individual to move from evaluation to training, to a work activities center, to a sheltered workshop or a competitive job, has been unable to accommodate many individuals with severe or multiple disabilities. Most of these programs require that individuals meet entrance and exit criteria before they are considered employable. Many of the programs have become bottlenecked, resulting in waiting lists of individuals who need services. Individuals with severe disabilities have not moved through this continuum successfully.

Rather than require individuals with disabilities to adjust to an artificial continuum, it is feasible to train and support them in an actual employment setting. This concept, supported employment, is more effective and less expensive than the traditional approach.

Supported employment is based on the following key ideas: 1) training is most effective when it is relevant, functional, and performed in the actual work settings; and 2) individuals learn best by modeling themselves after and learning from other individuals who are engaged in similar tasks. A great deal of natural learning occurs in this manner; this does not occur in segregated workshops.

Labels have very little value in developing learning objectives and support services for individuals with disabilities. Instead we need to develop functional analyses of the individual's skills and limitations, and compare them with the functional requirements of the job, allowing us to provide the supports required to compensate for a disability that inhibits job performance.

In the traditional continuum approach, staff members concern themselves with moving individuals from one segregated building to another. In the alternative approach, individuals are placed in the actual job setting immediately and services are provided as needed. Intensive services may be required initially, but as they are no longer needed, they are phased out.

Under the Consolidated Omnibus Reconciliation Act Amendments, supported employment is allowed under the Medicaid waiver. Medicaid should be restructured to discontinue "medical day treatment" in favor of supported employment.

B. What People Need

During the 1980's there has been a growing awareness of the rights of consumers and family members to make decisions about their lives, especially how funding decisions are made. Professor John McKnight of Northwestern University has noted that social service professionals have claimed the right to define what the problem is, what should be done about it, as well as to evaluate whether or not their solutions were effective. "Leadership becomes impossible when the claims of professionals are so comprehensive," McKnight says, because it strips clients of any personal sense of legitimacy or efficacy. The dignity of risk is lost. People become simply "clients" and society is encouraged to view them as social liabilities instead of social assets.

The growing empowerment of consumers comes into direct conflict with the Medicaid system as demonstrated by the following questions:

- Will individuals with disabilities be allowed to become as self-sufficient as possible or will they be encouraged to become overly dependent on professionals?
- Can the interests of caregivers and recipients be presumed to be the same?
- When conflicts arise between persons with disabilities and professional caregivers, whose interests will predominate?
- What is the impact of professional intervention (the formal system of care) on family and other (informal) system networks? Do present systems serve to supplement informal support networks or supplant them?
- Who decides how much care, and what kind, is to be rendered, when it is to be proferred and the setting in which it is to be delivered?
- Are such decisions properly the province of the professional, individuals, government or the family?
- What happens to the ability to leverage change on one's own behalf, when reimbursement is provided by an absentee third party, particularly when a public subsidy is involved?

The restructuring of Medicaid along the lines presented will result in better services to people with developmental disabilities, elimination of the wasteful funding of two systems, and services based on the needs of the individual rather than the needs of the system.

In closing, I would like to add that Senator John Chafee's bill, the Community and Family Living Amendments (S.873), would, if passed, contribute greatly to the reforms we have recommended. We hope the committee will thoroughly study it.

Senator DURENBERGER. Thank you very much.

John Chafee?

Senator CHAFEE. I want to thank both the witnesses a great deal. And, Dr. Wieck, I have had the privilege of hearing before, and she always does an outstanding job.

I would just refer to her testimony on page 3 where she says what I think is a very important point: "Compared to the billions spent on out-of-home placements"—that is, institutions—"less than 1 percent of the funding is designed for family support services." And I think that is a shocking statistic. And so I want to thank you, Doctor, and Miss Luckasson, both of you, for coming very much.

Dr. WIECK. Thank you.

Ms. LUCKASSON. Thank you.

Senator CHAFEE. Thank you.

Senator DURENBERGER. Do either of you have any special thoughts on how we do quality measurements, outcome? And somewhere between the words "outcome" which we have heard a lot of today and "quality" which we either presume or mischaracterize or whatever, do you have any thoughts on how society can come up with a measuring stick for outcomes, particularly as it relates to quality?

Dr. WIECK. I am glad you asked the question.

Next July Minnesota will return to court regarding the Welch consent decree, and in preparation for that case we have begun walking through the institutions, and beginning to compile information. In the consent decree it talks about the word "appropriate placement." And we have reviewed the literature. We have looked at the kinds of surveys that can be undertaken, and most of the surveys focus on input and process. Is there a program plan in place? Does it have goals and objectives that are measureable?

Senator DURENBERGER. Are the corridors wide enough for two wheelchairs, that sort of thing.

Dr. WIECK. What we are trying to do is take a look at the outcomes. And I briefly mentioned those at the end of my testimony. In other words, does this placement or service setting or regular home offer integration? And we can measure that. How much time is spent with nonhandicapped people who are not paid care givers? Does it foster productivity? And that can mean earnings. It could mean any number of type of contributions. Does it foster independence?

I worry about using adaptive behavior skills score changes, however, because it tends to keep people in service settings. If you are just going to perfect skill building, then all you are going to do is keep measuring more and more refinement of skill.

We have to look at age appropriateness, and that is a question you can ask. Would you actually do what we are requiring other people to do? And I think you can answer it yes or no. It doesn't require a lot of inter-rates reliability studies. We can look at the degree of integration in any number of ways.

So I think there are opportunities here, but I am not sure that the existing measures we have are focused in the right way.

Senator DURENBERGER. Thank you.

Ruth?

Ms. **Luckasson**. I would also like to suggest that a useful way to measure quality that has been often ignored in this field is to talk to the clients themselves about the quality of the services they receive, and ask them where they like to live, what they like to do, who their friends are, and how they want to spend their lives.

A second method that I would like to suggest, that is not quite as detailed as Dr. Wieck's suggestion, is that one of the things that is so valued and one of the things that we could attempt to measure within individuals who have developmental disabilities is the extent to which they participate in our common life, the extent to which they participate in the rich freedoms which we all desire and which we all treasure. And those measures tie into your initial statement about the freedoms of this country, and are a good way to evaluate the quality in their lives.

Senator **Durenberger**. A problem there, obviously, is that, to a degree, the family becomes a part proxy for the decisionmaking process. You said you can deal with the individual, and you can relate to the individual. And the individual is part of the evaluation. But in the next panel we will hear from the mother of a 6-year-old. You can't communicate with a 6-year-old on this subject but you sure can with the mother—the role that the family, as proxy or part proxy, plays in all of this often depends on family circumstances—and it isn't just the money that is available or the programmatic orientation and all that sort of thing

This makes the problem of outcomes or quality difficult to measure or address. But obviously as we search for these measurements in easier places, like in direct medical services, we also especially search for them in areas like this where much more subjective measures are necessary. So we will be highly dependent on organizations such as those you represent to help us in this regard.

Thank you all very, very much for being here. I appreciate it a lot.

Our final panel includes Jeff Gunerson who is a member of the board of the United Cerebral Palsy Association of south central Wisconsin, on behalf of the United Cerebral Palsy Associations; two of our past testifiers, directly or indirectly, from the State of Nebraska, who are going to be introduced by their Senator; and Dana Kruse, whom I have indirectly introduced before. She is here in her capacity as second vice president of Sick Kids Needs Involved People, or SKIP, from International Falls, MN, which is about as far north in this country as any of you are ever going to get. And I would suggest that you all go there sometime.

Jim, would you like to add an additional introduction to Dee and Pat?

STATEMENT OF HON. J. JAMES EXON, A U.S. SENATOR FROM THE STATE OF NEBRASKA

Senator **Exon**. Mr. Chairman, thank you very much.

A member of this very important committee, John Chafee, my friend, I appreciate your allowing me to come in this morning and introduce two of my constituents, two great Nebraskans that are here this morning, to give what I am sure to be very important testimony.

I would first like to tell everyone publicly that the two members of the Finance Committee, of which I am not a member, that are seated over here conducting this hearing, are individuals that have a deep involvement and a commitment to the less fortunate in our society, and I have had the pleasure of working with them on a number of issues very closely related to the matter at hand here this morning.

So I am delighted that they will be able to hear from two Nebraskans with intimate knowledge of the matter that we are discussing this morning.

I am pleased that you are holding this hearing and I congratulate you for calling it to examine the Medicaid funding for the long-term care of developmentally disabled persons.

As a former Governor, and before that as a private citizen, I have been actively engaged in and a strong supporter of improvement in all programs for mentally retarded citizens. I am pleased that you will be hearing from these two Nebraskans today.

Patricia Crawford is the government affairs chair of the Nebraska Chapter of the Mentally Retarded Association of America, and Pat sits on the extreme right of the expert witnesses that are before us now.

Next to her is Dee Everitt, and Dee is the chairperson of the Governmental Affairs Committee of the Association for Retarded Citizens. They have both been involved in mental retardation issues for a number of years, and both have personal and professional experience, and both will offer some firsthand testimony about the complex issues in this area.

We Nebraskans are proud of our accomplishments and our leadership in this tremendously important area. The progress has not always come easily, but our State has developed extensive community services at the same time that we have greatly improved the quality of care in our larger facilities.

From my point of view, the real issue about long-term care should not be the size of the facility, but the quality of the care that is being provided.

Parents and families of the developmentally disabled should have as many alternatives as possible from which to choose. And I appreciate very much the opportunity to come here. I am so delighted that these two Nebraskans have come forth. They are both experts.

And I would simply say that while there remains a great difference of opinion of how we should proceed, I would hope that we could come together more than we have, although we have made great progress. And I would simply caution, Mr. Chairman, that whatever legislation comes out of this hearing, we should continue our goal to recognize that, like all other people in the United States, our mentally retarded citizens are from a large and very diverse group. Many can do some things that others in my opinion cannot. Therefore, I think beyond anything else, when we approach changes we should approach those changes carefully, recognizing that there are all kinds of facilities for all kinds of mentally retarded people. And destroying one to create another does not necessarily mean that is good.

On the other hand, I would say to be against change just for the sake of being against change is not part of our philosophy in Nebraska either. So I am delighted that you are taking a look at this and I look forward to working with you and others as we move forward on this issue.

Senator DURENBERGER. Thank you, Jim, very much.

Well, let us begin. Jeff, you are first up. We welcome you here today. And all statements are paid of the record, so proceed to summarize.

STATEMENT OF JEFF GUNDERSON, MEMBER OF THE BOARD, UNITED CEREBRAL PALSY ASSOCIATION OF SOUTH CENTRAL WISCONSIN; ON BEHALF OF THE UNITED CEREBRAL PALSY ASSOCIATIONS

Mr. GUNDERSON. I thank you very much for letting me come here today.

I spent 10 years in institutions, and believe me, it wasn't pretty. Not for me it wasn't because of their treatments they gave me and the other patients there. I left to move in on my own in Janesville 5 years ago yesterday. So this is sort of an anniversary for me doing this today. And living on my own has been difficult, but it is a heck of a lot better than living in a State-owned facility that treats you like an animal.

I am also a member of the board of directors for South Central UCP, and I would like to give you some recommendations today on what I and other people hope that you would consider.

In 1971, the DD board enforced or tried to enforce their recommendations for State-owned facilities in my State, which is Wisconsin, and they spent $14 billion all over the country for nursing facilities, such as the one that I used to live in. And I don't think that is right because of the way they treated the people that I knew, including myself. But I am not here today speaking for myself. I am speaking for them.

Some people are not as lucky as I was 5 years ago to get out of the nursing home like I was. I wouldn't be out today if it weren't for the support of my county, doing what they are doing to keep us, the ones that are out, of there. And it is just not fair for the people that can get out.

The only reason that most of them are not out is because the State funding is lack, not just for the State of Wisconsin but all States, each and every one of the 50. And I just don't think it is fair. There are thousands and thousands of people like me that want to get out that cannot, and they get stuck in nursing homes for following their rules and regulations. And it is just not fair for people that can speak like I can and that is just the way it is.

Thank you.

Senator DURENBERGER. Jeff, thank you very much. You did a better job with your statement than most Senators would do in 5 minutes and I appreciate that a lot.

I guess, Dee, you are next.

Thank you very much.

[The prepared written statement of Mr. Gunderson follows:]

TESTIMONY

BEFORE THE

SENATE COMMITTEE ON FINANCE

SUBCOMMITTEE ON HEALTH

ON

THE MEDICAID PROGRAM AND LONG TERM CARE SERVICES

FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

RESPECTFULLY SUBMITTED

BY

UNITED CEREBRAL PALSY ASSOCIATIONS, INC.

WITNESS:

JEFF GUNDERSON

JANESVILLE, WISCONSIN

FRIDAY, SEPTEMBER 19, 1986

INTRODUCTION

Thank you Mr. Chairman for the opportunity to speak with you today about Medicaid funds for long-term-care for persons with developmental disabilities.

My name is Jeff Gunderson. I live in Janesville, Wisconsin. I am testifying today on behalf of myself and United Cerebral Palsy Associations, Inc. UCPA is a national network of 220 private, nonprofit agencies in 45 states. We are linked by a common objective--providing appropriate services to and advocating for the needs of persons with cerebral palsy and other individuals with similar severe disabilities.

You have had the opportunity this morning to listen to national experts in the field of developmental disabilities, federal officials, and state and local administrators of human service programs. You have heard a great deal about costs, spending trends, and statistics. I am one of those statistics--an individual whose life was affected by the so called "institutional bias" of Medicaid.

Today I want to do two things. First, I want to share with you my experience and the experience of two other individuals with developmental disabilities and second, I want to give you some recommendations for changes in Medicaid policy.

REAL LIFE EXAMPLES

None of the three of us are mentally retarded. Our disabilities result in substantial functional limitations in several areas of major life activity such as mobility, self-care, and economic self-sufficiency. We meet the test of eligibility for "related conditions" under Title XIX for provision of services in the ICF/MR program. Despite being eligible for services in this program, the majority of states have ignored the needs of people like us unless we also have a diagnosis of mental retardation.

Let me tell you about Jack. He was born with cerebral palsy. When he was four years of age, his parents were unable to cope with his needs. At the recommendation of their family physician, they placed Jack in a state institution. Although of above average intelligence, Jack remained in the large state facility for 21 years. As part of a so-called "deinstitutionalization" mandate resulting from a court decree, Jack was placed in a nursing home where he has resided for the past 10 years. Jack is 35 years old. His co-residents average over 70 years of age. Jack moves about in an electric wheelchair and communicates with staff with a portable voice activated computer. The computer was purchased by staff as a result of their own private contributions. It was not paid for by the "system". There are no planned activities, and most of Jack's time is spent following the staff around the facility.

Jack is not sick! He is not in need of nursing or medical care which are the primary services provided by the nursing home. The only reason Jack lives in a large intermediate skilled nursing facility subsidized by Medicaid is that the personal attendant services he needs are not paid for under Title XIX in his community. Jack told staff at the UCP of Detroit, "I want a way out". Unfortunately, Jack must continue to reside in a restrictive and inappropriate setting for at least three more years before an accessible apartment and personal support services may be available. I don't believe this is an effective or efficient use of our financial or our human resources.

Let me tell you also about Karen. She has cerebral palsy and used to walk with a walker, but is now in a wheelchair. Karen went to school until she was 18, and has lived at home ever since. She is now 37 years old and lives with her parents who are 65 and 67 years old. They cannot continue to lift their daughter out of bed, to dress her, to put her in their car, and they don't know how much longer they will live. They have been advised to place her in a nursing home or institution, but have heard of bad experiences in those facilities. Her parents, who live in a remote desert area of California, wrote recently to the UCPA national office seeking an answer in terms of their daughter's current and future long-term support service needs. No other options are available to Karen and her family in their home community!

Let me tell you about Jeff Gunderson. I lived with my parents until I was 18, and attended the public schools. When my parents got divorced, it was too much of a struggle for my mother to keep me, and I was placed in a nursing home. My mother was not offered any support services as an alternative so that I could remain at home.

Five years ago yesterday, I moved out of the nursing home into my own apartment with full-time attendant support services. And that almost didn't happen because many professionals think you have to go through a "continuum" of places like group homes before you can live in an apartment. How silly. I'm here to tell you that people like me need support services and a decent place to live in the community, like everyone else. We don't need to go through four to six less and less restrictive "facilities" in order to graduate to an apartment. In fact, if UCP of Wisconsin and our Wisconsin Developmental Disabilities Council had not committed money to try this approach, I'd probably still be in the nursing home.

I don't like thinking about the ten years I spent in the Medicaid funded nursing home. It was awful. I felt lost and forgotten. I had nothing in common with the people I lived with. Most of the other residents were elderly or mentally retarded and physically handicapped. When people my age in the community are just starting to have a good time, we in institutions are all getting ready for bed. I was considered a behavior problem because I didn't want to go to bed at seven o'clock. My punishment for not complying was a cold shower--very painful for someone like me with spastic muscles. I lived in a nursing home even though I am not sick, don't need nursing or medical services, and don't want to be dependent. Even though I have some friends back at the nursing home, I don't like going back to visit.

Today, I live in an apartment subsidized by HUD funds. My full-time attendant, who provides me assistance in dressing, bathing, and eating, is supported by my SSI and state funds. Until I had a chance to live on my own, I didn't know what I was missing. I had been deprived of common life experiences so many people take for granted.

This is the first time I have ever been to Washington, D.C. Yesterday was the first time I ever flew on an airplane. Although I am more than a little nervous, I wanted to come here today to testify on behalf of all persons with severe physical disabilities who, like myself, were deprived and continue to be deprived of the opportunity to be more independent. My serious physical disabilities hide from others my real capabilities to make choices and enjoy living.

MEDICAID

Medicaid is an entitlement program. It shares fiscal responsibility with the states for the "long-term-care" needs of persons with developmental disabilities. More than 15 years ago, the ICF/MR program was added to ensure that persons like me are provided a certain level of care that includes active treatment--not a living death!

In 1985, Medicaid spent $14.7 billion for nursing home care, more than one-third of total Medicaid spending. In several states, nursing home payments account for almost two-thirds of the state's Medicaid budget.

The range of services needed by persons with developmental disabilities is as diverse as the population in need. There is a need for a full array of personal, individualized health, social, habilitation/rehabilitation, and personal support services over an extended period of time.

Long-term-care services can be provided in a variety of settings -- at home, in the community, and within institutions. Unfortunately, only one dollar of every four that Medicaid expends on long-term-care services for persons with disabilities is spent in a home or small community setting.

I live in my own apartment. Each day of the week, my attendant assists me with bathing, eating, dressing, and getting around our community. I enjoy my freedom; an array of support services made possible by federal and state financing that costs about 25 per cent less on a monthly basis than what it costs the federal Medicaid program for custodial care in a nursing home where you have no sense of personal worth and dignity.

CONCLUSIONS BASED ON UCPA'S SERVICE EXPERIENCES

UCP has been providing community, residential, and support services in forty states for over twenty years. Based on our experience, the following conclusions have been reached:

1) The continuing institutional bias of Medicaid in the ICF/MR program fails to respond to individual needs by rewarding states for the use of congregate care, facility based services for persons with developmental disabilities: young children are denied their right to grow up in a family; adults with severe disabilities are denied the freedom of choice as to where they can live.

2) The strict interpretation of HHS that limits the definition of habilitation services to pre-vocational activities deprives thousands of persons with developmental disabilities the opportunity to become more independent, productive, and partially self supporting tax payers;

3) Almost no one with developmental disabilities needs to be in an institution, because for each individual in a Medicaid funded large institution, there is an individual with virtually identical disabilities and levels of service need now living successfully in a community setting;

4) The overall cost of individualized home and community services is equal to or less than the group cost of providing comparable services to individuals with similar levels of need in an institutional setting;

5) Families who have struggled and sacrificed to keep their son or daughter at home are now being penalized for their efforts. The Home and Community Care Waiver primarily targets those individuals who have been institutionalized for new community services and places individuals living at home on the longest waiting list for such services; and

6) The primary reason persons with developmental disabilities are not able to remain in their natural home or a real home of their own choice is the failure of Medicaid to reimburse for an array of personal support services except under a limited Home and Community Care Waiver.

SERVICE PRINCIPLES

UCPA believes Medicaid public policy has not kept pace with the current state of knowledge and best practice for effective service delivery for persons with developmental disabilities. Recently, UCP of Indiana adopted the following set of principles to guide future service planning and development:

- Services must be available to persons living in their natural home or a home of their choice. Relocation must not be a necessary condition to access services. Services and funding must be available and follow persons with disabilities regardless of the setting.
- Services must be provided based on individual needs, not related to restrictions of specific funding services. The provision of services must not be based on the availability of services.
- Service goals must be directed toward physical and social integration in one's own community. Services must be delivered in a manner which uses positive interventions and promotes enhanced images and valued social roles of service recipients.
- Services must utilize and foster the development of community generic resources. (Training must focus on acquiring functional, useful skills and using community resources.) Services must minimize the need for skill transfer by providing training in the environment in which the skills are required.

- Services must respect personal preferences and desires of those served. Services must maximize the autonomy and independence of consumers. Multiple options/providers must be available to individual consumers in each service category.
- Service recipients must participate in the planning, operation, and evaluation of services. Services should maximize the participants self-direction and control leading toward self-governance.
- Service recipients must be supported in a life style and setting of their choosing and typical of their peers. Services must assist residents in participating in community activities with non-disabled peers. Services must utilize the least restrictive environment in which needed supports can be provided.
- Priority for services must be given to persons with more severe disabilities who have greater support needs.
- Services must be flexible to provide a variety of support options in varying intensity according to each individual's needs. Residential support services must be coordinated with all other service components including, but not limited to; employment, social and transportation.

RECOMMENDATIONS

The well intentioned Medicaid long-term-care program for persons with developmental disabilities, begun in 1971, has become entrenched. We now have an outmoded, ineffective, inefficient service model being reinforced and expanded with a public policy of federal financing. You have the power to stop this trend today and bring the Medicaid program into harmony with all other congressional mandates concerning persons with disabilities such as those articulated in: 1) the Education for All Handicapped Children's Act of 1975 (P.L. 94-142); 2) the Rehabilitation Act of 1973 and current amendments now in conference committee for reauthorization including a major commitment to employability and integrated, supported employment rather than sheltered workshops for persons with severe disabilities; and 3) the Developmental Disabilities Act of 1984 (P.L. 98-527) with a declaration that all services to persons with developmental disabilities should result in the measurable outcomes of increased independence, productivity and community integration.

UCPA commends Senators Chafee, Weicker, and Bradley for the respective pieces of legislation they have introduced to reshape Medicaid policy in concert with these other landmark laws of our country.

As William Shakespeare said, we must "suit the action to the words." We urge you to begin Medicaid financial policy redirection today by considering the following amendments to current Medicaid law through the Budget Reconciliation Act in Conference Committee.

1. Redefine the ICF/MR as a program for persons with developmental disabilities to provide family and community residential services and comprehensive, long term, personalized support services;
2. Establish as the goals of the program, increased individual independence, productivity, and community integration as defined in the Developmental Disabilities Act of 1984;

3. Provide an assurance that all individuals with mental retardation or a "related condition" are eligible for such long term personalized support services including, at a minimum:
   - o an assessment of functional needs for eligibility;
   - o the convening of an interdisciplinary team to prepare a comprehensive individualized plan of services leading to the above stated outcomes;
   - o the assignment of a case manager who is independent of the provider system; and
   - o the person's freedom to choose service models and providers with procedural safeguards;
4. Provide the states greater flexibility to meet individual needs by:
   - reducing burdensome process/paper regulations;
   - increasing the accountability of states and providers for having trained, competent staff;
   - assuring that individuals benefit from services by achieving measured increases in functional independence, productivity, and community integration;
   - allowing the states to provide a full array of services similar to the Home and Community Care Waiver including individualized family support services and supported employment; and
   - increasing the federal reimbursement by 5% for small community living arrangements and comprehensive support services and reducing the federal reimbursement by 5% for any congregate care and institutional services.

Please do not let another three and one half years go by where nothing has changed and 75% of the Medicaid dollars continue to support dependence, regression, and segregation. I urge you to act today on behalf of thousands of people with developmental disabilities who want the opportunity to become independent and to live, work, and recreate in the real community. Let us create a policy that assures human resource development and does not hold people back from life.

Thank you.

STATEMENT OF DEE EVERITT, CHAIRPERSON, GOVERNMENTAL AFFAIRS COMMITTEE, ASSOCIATION FOR RETARDED CITIZENS OF THE UNITED STATES, LINCOLN, NE

Ms. **Everitt**. Thank you, Senator Durenberger, and other members of the committee, and thank you, Senator Exon, for your kind remarks.

Senator **Durenberger**. Let me thank his attendant here too for being so helpful. All of us have attendants with us when we are on the floor and putting those papers in front of us and so forth. And Jeff has done a lot better job than—he must have a better attendant than we have. [Laughter.]

Mr. **Gunderson**. Yes; I do.

Senator **Durenberger**. Great. Go ahead, Dee.

Senator **Exon**. He also has more people listening than the others. [Laughter.]

Senator **Durenberger**. Yes.

Ms. **Everitt**. I wish to thank the committee for holding this hearing and allowing ARC to present its views regarding Medicaid long-term care. I just finished a 2-year stint as the national president of the ARC of the United States.

The Medicaid ICF/MR Program and the Waiver Program are very critical to people in the lives of people who are able to use the services; however, the Medicaid ICF/MR Program and the Waiver Program do not work for eligible people who cannot get access to these services which, in our opinion, now work only for a limited portion of people in a package that is "one-size-fits-all."

The ARC has long been a champion for improved quality of services, and for that reason we applaud the Congress for providing the ICF/MR Program which has done so much to clean up institutional conditions over the last 15 years. However, the original goals and the current administration of this program have lost step with the goals of eligible individuals and the families who need the services.

I think the Finance Committee now has a perfect opportunity before it to correct this and to work toward improving the Medicaid long-term care program so that it will work for the people that it was intended to serve.

Over the past 2 to 3 years I have traveled in probably 35 States. Everywhere I traveled people have asked me why they cannot use Medicaid services in the community or in their own homes so that they can keep their kids with them. I have not been able to positively respond to these questions, except to suggest that we are trying to get changes made.

I suggest that the Finance Committee does have the power to make this change and to provide a resource to these people. I am hoping that you will very seriously look at this situation.

We have submitted extensive written testimony on these concerns, including a list of principles for reform. I just want to briefly mention a few of them.

Federal policy and Federal financial participation should recognize and support service provision in settings which stress increased family and community integration and which stress an individual's growth and development toward increased independence and maximum self-sufficiency.

Reform measures should encourage decreased reliance on large facilities, based not on the comparison of cost, but on the needs and the rights of the individual.

Reform measures should recognize the long-term effectiveness of providing home and community based services to persons with mental retardation.

Reform measures must give the States increased flexibility in their program design and in the array of services which they may provide to meet the needs of individuals.

Reform measures must make the Federal partnership in home and community-based long-term care reliable and effective.

Reform measures must continue to ensure the quality of services provided by all participating providers and the protection of the rights of individuals receiving Medicaid services.

Members of the committee, you now have before you, in written and oral testimony, a wealth of information on current public policy, spending, population characteristics, and trends.

I would like, however, as a parent, to leave you with this. Behind all of the facts and the figures are people; people who need certain services in order to participate more fully in our society; individuals who deserve to be treated with the respect and dignity that is due every citizen. Many, many people struggle to provide themselves or their family members with the services they need in order to maintain the greatest degree of independence possible and to maintain ties with families and friends. When the Federal Government steps in to provide services to persons in need, it should do so in a manner consistent with these goals. It should do so in a manner which respects an individual's established family and community relationships, which respects the expressed needs of the individual and family, and which supports rather than destroys the fabric of one's life.

I want to assure you that my daughter, who is 34 years old, who is multiple handicapped, who is the typical kind of person who 30 years ago was placed in an institution, has not ever been institutionalized. For us, this was never considered as a viable option. She has mental retardation. She has cerebral palsy and she has a chronic seizure disorder with 10 seizures a day at the minimum.

We have never felt that this was a reason to isolate her from her brothers, and her mother and her father and her family. However, I would like to see her continue living in the community when we are gone so she can continue her relationship with her brothers.

Thank you.

Senator DURENBERGER. Thank you very much.

Pat, it has been a long time getting you here. And every time we have one of these hearings your former Governor keeps beating up on us. And we are glad you are able to be on this panel today and we appreciate the opportunity to listen to your testimony.

[The prepared written statement of Ms. Everitt follows:]

(Short)

TESTIMONY

BEFORE THE

SENATE COMMITTEE ON FINANCE

SUBCOMMITTEE ON HEALTH

ON

THE MEDICAID PROGRAM AND LONG TERM CARE SERVICES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

RESPECTFULLY SUBMITTED

BY

ASSOCIATION FOR RETARDED CITIZENS OF THE UNITED STATES

WITNESS:

DEE EVERITT
CHAIRPERSON, ARC GOVERNMENTAL
AFFAIRS COMMITTEE

FRIDAY, SEPTEMBER 19, 1986

I. INTRODUCTION

The Association for Retarded Citizens of the United States is a national organization of volunteers - parents, educators, professionals in the field of mental retardation, self-advocates and others. The ARC has been in existence since 1950. Currently, our membership consists of approximately 160,000 individual members, over half of whom are parents of individuals with mental retardation. The ARC is the largest organization in this country representing and promoting the rights of persons with mental retardation and their families. We thank you for this opportunity to express the views of the ARC regarding Medicaid long term care services for people who are developmentally disabled.

We are in a new age in the field of mental retardation. Parents with young disabled children no longer must consider sending their child away from home to receive care, training, and education. Indeed, the passage of Public Law 94-142, the Education for All Handicapped Children Act, and the availability of educational and certain other services within community settings have practically erased the word "institution" from the vocabulary of these parents. The use of institutions is not, and will never be a desired option for them.

With more families able to keep their children with disabilities at home, there is now a growing demand for sophisticated, stable services systems within our communities. New experiences and new knowledge have created very different expectations from those of the past. It is time to let go of the old models and ideas and embrace the new ones. And it is the responsibility of the federal government to respond to these new experiences and this new knowledge and promote better services, better practices and better lives for our nation's citizens with mental retardation and other developmental disabilities.

II. HISTORICAL PERSPECTIVE

Since this nation's earliest history, people with mental retardation who have needed assistance or care beyond what their families were able to provide have been subjected to a segregated system of service provision. Although the earliest residential schools were designed to educate persons with mental retardation, teach them an occupation, and return them to their home communities and/or families, the increased use of institutions for custodial care changed the nature and purposes of institutions. With the eugenics movement, institutional purpose again began to shift: from the desire to protect the person with mental retardation from society to the desire to protect society from the person with retardation. Conditions in institutions were described as horrible in the contemporary literature; and, although great strides have been made in improving institutional quality, scandalous conditions continue to persist today. (See Senate Hearing Record 99-50, Joint hearing by the Senate Subcommittee on the Handicapped and the Senate Appropriations Subcommittee on Labor-HHS-Education.)

The legacy of our history in providing care in large segregated facilities remains with us today in the form of large public and private facilities providing long term care for persons with mental retardation in situations often isolating people from their families and home communities. The legacy of segregated care also remains a strong influence on our long term care system because major elements of our society have yet to develop overriding public policies and systems to meet the needs of families and persons with retardation where the need arises: at home or in their home communities.

The federal government's contribution to long term care for persons with mental retardation is primarily through the Medicaid Intermediate Care Facilities for the Mentally Retarded (ICF/MR) program authorized in Title XIX of the Social Security Act. The ARC recognizes the major role that the ICF/MR program played in improving and upgrading the conditions of large public and private facilities for persons with mental retardation over the past 15 years. The ARC also acknowledges the significance of the declining numbers of people living in large state mental retardation facilities and the growing numbers of small ICF/MR facilities (of 15 beds or less) scattered throughout this nation's communities. However, the bulk of the federal government's participation in long term care for persons with mental retardation remains based on the institutional concept of 24-hour care facilities requiring that persons needing services must live away from their own homes or families. The ARC believes the time has come for the federal government to engage in a serious restructuring and refocusing of its participation in the provision of long term care services to persons who are mentally retarded or developmentally disabled.

III. RECOGNIZED PHILOSOPHIES OF SERVICE PROVISION

The years since 1971 during which the ICF/MR program was conceived and developed were critical years of change in principles and philosophies of care in general for persons with mental retardation. The philosophies of care which have developed over the last 15 years and the technologies developed to implement them differ dramatically from the philosophies which led to the growth and development of large residential facilities.

Current social and philosophical concepts which shape the prevailing view of appropriate long term care for persons with mental retardation are complementary and overlapping. The concepts include: family support and family-based care when possible; the developmental model of service planning as more appropriate than the medical model for persons with developmental disabilities; normalization; habilitation; least restrictive environment; nondiscrimination on the basis of severity of handicap; and increased and maximized independence on the part of the person with mental retardation. These philosophies and concepts run throughout educational programs, residential programs, family support programs, and programs for vocational assistance and employment.

In short, the prevailing concepts recognize each individual as someone with developmental potential which can and should be maximized to allow the person the greatest economic and personal independence possible, with the least possible restriction on personal liberty and rights, and with the opportunity and training to enable the individual to live within the patterns and conditions of everyday life in his own community and the regular circumstances and ways of life of his society. The philosophies emphasize services to assist individuals and families at home or in community - integrated settings. The emphasis is on decreased institutional admissions and the movement of institutionalized people back into community settings with proper training and support systems.

Service systems which reflect these philosophies have developed numerous residential alternatives to the 24-hour model of residential care, including in-home assistance and family support, group homes, supervised living arrangements in homes and apartments, adoptive families, and foster family arrangements. In fact, family support, whether for a natural, adoptive, or foster family, is increasingly the trend for providing long term care services to children with mental retardation; non-familial settings such as group homes, nursing homes, ICF/MRs, and public or private institutions are increasingly being considered unacceptable service settings.

In any discussion of the current principles and philosophies which guide service provision, a factor which cannot be overlooked is the impact which P.L. 94-142, The Education for All Handicapped Children Act, had on people with mental retardation, their parents and families, and the professionals and advocates who serve them. After a decade of public school education for children with severe disabilities, our knowledge about teaching methods and perceptions about the capabilities of persons with severe disabilities have changed dramatically. The expectations and demands of parents, consumers, professionals, and advocates have moved many stages beyond the expectations which prevailed when the ICF/MR program was initiated.

The trends in education towards the least restrictive setting and increasing personal independence through acquisition of necessary skills are being carried forward into employment initiatives. The focus in employment is to give persons the opportunity to work in as fully integrated a setting as possible. Whether the work is fully competitive or whether special support services are needed, it is recognized that severely disabled people, once thought unemployable, are capable of working and achieving at least some degree of independence. Throughout programs funded by the U.S. Departments of Education and Health and Human Services there is increased emphasis on work incentive initiatives and programs which encourage and foster the handicapped student's transition from school into competitive or supported work.

Families in situations which 10 or 15 years ago may have forced them to institutionalize a child in order to get needed services, have instead seen their children educated in the public school system. We now have numbers of educated young adults with mental retardation who are "aging out" or getting too old for eligibility for services through their local school systems. Because of their training, they have much greater opportunities to find a place, integrated within our communities, to live and work than did young adults 10 years ago. But service needs of people with mental retardation do not end at age 18 or 22; these individuals and their families are still in need of external support systems. Furthermore, these individuals and families are no longer willing to accept the 24-hour residential care facility as the only option.

Another factor which must be considered is the current trend in deinstitutionalization of large public facilities which is taking place across the country as a result of court orders and, in some cases, on the initiative of the state. That trend, coupled with a declining rate of admission of children and adults to such facilities, is resulting in a steady decrease in the overall population of persons with mental retardation in large public facilities.

IV. CONFLICTS BETWEEN PHILOSOPHIES OF SERVICE AND THE MEDICAID PROGRAM

Increasingly, parents and consumers have been demanding more individualized family and consumer support services at home and in their communities while the total population in large public facilities has been declining. However, the Medicaid ICF/MR program still maintains an emphasis on 24-hour out-of-home care.

There are several areas in which the Medicaid program as it is now structured conflicts with the needs of people with mental retardation and their families. The major areas of conflict will be examined here.

Any discussion of Medicaid's role in the provision of long term care services to persons with mental retardation inevitably raises the issue of the purpose of the Medicaid program itself. Administered within the Health Care Financing Administration, Medicaid is usually viewed as a program with an essentially medical focus. While the ARC has attempted over the years to emphasize direct services based on development, learning, and the acquisition of new skills rather than services with an exclusive medical "treatment" focus, families, consumers, providers, and advocates often are faced with medically-oriented treatment systems and concepts. It is important for Committee Members to note the two purposes of the Medicaid program as put forth in Section 1901 of the Social Security Act. The dual purpose is to enable each state to furnish:

> 1) medical assistance on behalf of families with dependent children and of aged, blind, or disabled individuals, whose income and resources are insufficient to meet the costs of necessary medical services and 2) rehabilitation and other services to help such families and individuals attain or retain capability for independence or self-care,....(emphasis added)

"Habilitation" is the term used to refer to services provided to persons with developmental disabilities which are designed to assist the individual to attain, as much as possible, capability for independence or self-care. A recurring issue in Medicaid long term care service provision is the question of what services should be eligible for reimbursement to the states under the term habilitation. Advocates, state administrators, and providers have sought, unsuccessfully, to get a definitive answer from HCFA which reflects current professional opinion. The question centers on the amount of overlap between "habilitation" and educational and vocational services. In its March, 1985 rules for the Home and Community-Based Care Waiver program, HCFA has taken the position that "waiver" services must enable individuals to accomplish those day-to-day tasks necessary for them to remain in the community and avoid institutionalization. HCFA states:

> We do not believe that prevocational and vocational training and educational activities are commonly furnished as a means of avoiding institutionalization. Individuals would not, in the absence of such services, require institutionalization.

Although Congress has dealt with this waiver coverage problem to a limited extent (COBRA-85), the issue still exists for segments of the waiver program and for the entire ICF/MR program. HCFA's statement flies in the face of reality, against both the service needs of individuals and families and the current body of knowledge concerning people with developmental disabilities. It is also in conflict with policies of other Department of Education and HHS programs. This one Medicaid policy illustrates a very basic problem underlying all Medicaid long term care services to persons who are mentally retarded: the program and its administration are out of step with the needs of people who use the services and with the current body of professional knowledge and policies regarding appropriate service provision.

As was noted earlier, parents and individuals with mental retardation are often seeking services far less extensive than 24-hour care facilities. Depending on the particular circumstances of the family or individual, service needs might be limited to several hours a week. But when an individual or family is faced with no services to support family or community-based care, that individual may be forced to join the ranks of those receiving 24-hour, residential facility-based care in an ICF/MR. This is unnecessary, unwarranted, and is a waste of valuable resources. Many individuals currently on waiting lists for ICF/MR or other public or private facility services might possibly avoid out-of-home care if alternative support systems were in place.

What is often referred to as the "institutional bias" of the ICF/MR program is the result of a combination of factors. The program is facility-based, with states receiving reimbursement only for services to persons living in Medicaid-certified facilities. The program originally focused on assisting states to improve conditions in large public institutions and the bulk of ICF/MR funds have been used in the large congregate settings. Large ICF/MR facilities, both public and private, often mean that individuals who live there are geographically far from home and family since many facilities were constructed many years ago in rural areas. Distance from family and isolation from home communities adds to the institutional impact. In addition, the Medicaid eligibility provisions which deem parental income as available to children living at home while not deeming such income available to children living in institutions or out-of-home create an impossible choice for parents. They are faced with choosing between Medicaid assistance for their child in out-of-home care or no Medicaid assistance while the child remains at home.

The 24-hour facility focus of the ICF/MR program also creates another problem for people with mental retardation who need services: access to services. This problem presents itself in two ways. First, since states may limit the number of ICF/MR certified beds in the state, eligible people who need ICF/MR level of care and who therefore should receive the services on an entitlement basis, are in practice denied services while their names get added to waiting lists. Secondly, if Medicaid supported services of a less extensive nature than ICF/MR services were available for people at home or in their communities, many persons would never need the ICF/MR level of care. We are well aware that the "need for institutionalization" often depends more on family circumstances and the support available than it does on any level of severity criteria. Lest this discussion raise the spectre of the "woodworking" effect, please remember, first, that eligible individuals now go without needed services under a federal entitlement program, and, secondly, that the criteria to establish disability severe enough to qualify persons for Medicaid are not easily abused. Furthermore, we believe that individuals and families are looking for reasonable cost effective in-home or community assistance to meet their individual needs.

The Home and Community-Based Care Waiver program does allow states some flexibility and relief from the 24-hour facility focus of the ICF/MR program. The waiver program has given us an opportunity to see creative program alternatives to the ICF/MR program which serve people at home and in small community-based settings. However, the waiver program is limited in its ability to provide states with a federal partner for the development of a comprehensive community based service system that can be relied upon for the future. Waivers are dependent upon Secretarial discretion; waivers are granted initially for 3 years and renewed for only 5 years; waivers are an exception to a service system which stresses the 24-hour model of care; services are based on level-of-care and cost-of-service criteria rather than on individual need; and the administration of the waiver program in recent years has served to restrict and confine the use of waiver services to meet the needs of persons with mental retardation.

V. MAJOR AREAS FOR MEDICAID REFORM

It is clear to the ARC that the time has come for major reforms in the Medicaid system of long term care for persons who are mentally retarded. There are several principles and concepts which we believe need to be a part of any reform product.

o Federal policies and federal financial participation should recognize and support service provision in settings which stress increased family and community integration and which stress an individual's growth and development towards increased independence and maximum self-sufficiency. Policies based on anything less are selling short two of our nation's greatest resources - its people and its diversity.

o Reform measures should encourage decreased reliance on large facilities, based not on a comparison of cost, but on the needs and rights of individuals to receive effective services in settings which impose the least restriction on personal liberty. In 1984, the ARC issued a position statement on residential opportunities which includes a call for the eventual phase out of the institutional model of care because of institutions' "lack of success in providing essential developmental opportunities needed by persons who are mentally retarded."

o Reform measures should recognize the long term effectiveness of providing home and community-based services to persons with mental retardation. Services that are provided when needed and where needed to individuals and their families can be extremely effective in reducing the extent of an individual's need for partial or total long-term care services over a lifetime.

o Reform measures should eliminate the institutional or facility bias in long term care service provision. What has been termed the "one size fits all" approach to services should give way to allow states to offer long term care services on an individual need basis, or an "a la carte" approach to designing a set of services to suit each eligible individual's circumstances and needs. Such an individualized, non-facility-based system would require a well-designed case management system to ensure proper development and implementation of a service package to meet the needs of each eligible person or family.

o Reform measures must give the states increased flexibility in program design within stated goals and service principles. State systems are currently in various stages of development of community-based services and reliance on institutional or facility-based care. States will also require flexibility in the array of services which will be offered to meet the needs of individuals in their states.

o Reform measures must make the federal partnership in home and community-based long term care reliable and effective. As discussed, the current waiver program commitment on the part of the federal government cannot be relied upon by the states for long term planning.

o Reform measures must take into account the social and philosophical principles which are currently guiding families, advocates, and professionals in their quest for services. Effective service provision cannot be achieved if the federal government's role is out of step with other responsible parties and individual service needs, as is the case now with the issue of "habilitation."

o Reform measures must continue to ensure the quality of services provided by all participating providers and the protection of the rights of individuals receiving Medicaid services.

o Reform measures must escape the institutional legacy of our nation's past and ensure service provision based on respect and concern for the dignity of each individual and respect for the rights of each individual as a citizen.

o Reform measures must ensure that services go beyond the medical model and provide habilitation services not otherwise available and truly designed to assist the individual and his/her family attain and retain capability for independence and self-care. Such services should include, among others, case management, personal and/or attendant care, repite care, family support and training, adult day training programs, specialized vocational services, specialized transportation, and preventive services.

VI. S.873 AS A MEANS TO ACHIEVE REFORM; OTHER LONG TERM CARE REFORM BILLS

The ARC has spent considerable time and effort in reviewing the Medicaid long term care system and in considering the reforms and amendments necessary to address the needs of eligible persons with mental retardation and their families. We believe that the Community and Family Living Amendments of 1985 (S.873 and H.R. 2902) would achieve reforms which reflect recognized philosophies and principles of service provision. S.873 should be carefully considered by the Finance Committee as one approach to solving the problems and issues which are raised by this hearing. The major provisions of the Community and Family Living Amendments (CFLA) are designed to do the following:

o Require states, as a condition of receiving federal funds for certain services not now available under their existing state Medicaid plans, to engage in long-term systematic planning of coordinated community and institutional service delivery systems affecting people with disabilities.

o Ensure quality services for persons who are institutionalized and for those living at home or in community settings.

o Involve clients, parents, and/or families in the decisions affecting a person with disabilities.

o Require service provision to be based on an individualized plan developed by an interdisciplinary team including participation by the individual who receives the services, as appropriate.

o Require that states include some "community and family support services" in their Medicaid plans beginning two years after the effective date of the act. A comprehensive list of services that the states may choose from is included with a mandate for provision of case management services, protective intervention services, and individual/family support services (which would include non-medical personal assistance and respite care).

o Make federal Medicaid reimbursement to the state conditional on completion of an implementation agreement between the state and the Secretary of Health and Human Services (HHS). Such agreements must cover a range of issues (quality control, protections of individual rights, training of employees, audits and monitoring arrangements, a plan for increasing community resources and decreasing reliance on large institutions, among others) and each agreement would be composed by the state in the light of circumstances prevailing in the state.

o Make gradual reductions in the percentage of federal Medicaid match as it applies to care in Medicaid-certified long term care facilities accommodating more than 15 residents.

o Place a limit on a state's expenditure of Medicaid funds in institutional settings after 14 years.

The ARC stands willing and eager to work with the Finance Committee and its staff to further improve CFLA within its basic concepts and goals and looks forward to its passage.

The ARC is also aware that other approaches have been proposed to address the need to allow states more freedom to offer home and community-based services through Medicaid, such as Senator Weicker's bill, Quality Services for Disabled Individuals

Act of 1985, S.1948, and Senator Bradley's and Representative Wyden's bills, the Medicaid Home and Community-Based Services Improvement Act, S.1277 and H.R. 2863. Our initial analysis of these bills, however, reveals that eligibility is based on an individual's "need" of institutionalization and a comparison of cost between institutional care and home or community-based care. Although we are very concerned about any reform approaches which have an institutional model at the base of service provision, we would be happy to continue work with the sponsors of the bills and the Finance Committee to restructure them in line with individual service needs outside of an institutionally-based system.

VII. CONCLUSION

Given the practical limitations of space and time, our testimony has necessarily had to skim over or touch only briefly upon issues and concepts which are of critical importance in this discussion of Medicaid long term care services to people who are developmentally disabled. Should the Committee Members or staff wish further detail, information, or discussion about any area of our testimony, including concepts or principles of service provision or concerns regarding the current Medicaid structure, we would be happy to provide it. In addition, the ARC would be happy to refer Committee Members and staff to relevant studies and literature in the field, to experts in policy and service provision, and to parents and families who could illustrate the issues from their own experiences.

Thank you for this opportunity to present testimony before the Subcommittee today. The ARC looks forward to the Finance Committee's consideration of the issues presented here and we look forward to working with Members and staff in ensuring that services which the federal government supports through Medicaid are redesigned as rapidly as possible to truly meet the individual service needs of eligible persons and their families.

STATEMENT OF PATRICIA CRAWFORD, GOVERNMENTAL AFFAIRS CHAIRMAN, MENTAL RETARDATION ASSOCIATION OF NEBRASKA, INC., LINCOLN, NE

Ms. Crawford. I am glad that I have Mr. Exon to be my champion. I thank you very much; I appreciate your efforts. You know, he feels very strongly about this subject. He has got a lot of bruises on him from his governorship.

In fact, when he was Governor, I was appointed to the Nebraska Governor's Developmental Disability Planning Council and I still serve as vice chairman of that group.

Last night I had the opportunity to meet with parents of adult Medicaid recipients from six other States, sort of a chance meeting with some of the people I have talked to on the telephone over the years, but we haven't met face to face until last night.

These people feel so strongly about this issue that they came to be at this hearing today even though they could not speak. And they said, "Pat, you are the only one, so speak for us." So I am going to do the best I can.

You probably saw the recent U.S. News & World Report success story about retarded people, "Back in the World and Doing Just Fine," and you may remember Mickey Rooney's portrayal of "Bill," a real life mildly retarded man making it on his own. I am going to tell you about an unsuccess story about a real life man with profound retardation, and an IQ measured at zero.

My 25-year-old son, Matt, is a resident at the Beatrice State Developmental Center for the past 11 years and he is very representative of that population classed as "severely or profoundly handicapped." These folks are very different from the folks with retardation who live in your community. Matt lived at home with his mom and dad, older brother and sister, and younger brother and sister until he was 14 years of age. He attended schools from age 3. The public schools did not take handicapped kids at that time, so we parents worked real hard at raising funds to keep the schools running.

As Matt grew into the teen years, it became apparent that the programs that we had helped to establish did not meet Matt's needs at all. He needed a structure and a routine that only an institution can provide. He has no speech at all.

We wanted him to be where there are three shifts of staff rather than house parents who can wear out. We like the checks and balances and the high profile of a residential center; we like the rules, the Medicaid rules, that insure high standards.

Matt needs direction in every activity. He needs help bathing and shaving; he must be told what to wear, when to eat, when to brush his teeth and wash his hands. He likes to swim in the specially designed pool and it is wheelchair accessible. He likes music. But I can honestly say that because of profound retardation, there is really little else he can do or even seems to care to do.

The reality is that Matt and the folks like him can never live up to the expectation Senator Chafee expressed when he introduced S. 873. He said, My legislation rediscovers the values of freedom, meaningful work in the neighborhood by giving mentally retarded and physically disabled individuals and opportunity they have long been denied.

At the Beatrice State Developmental Center where Matt resides, 389 of the 467 residents are multiple handicapped; 238 have seizure disorders; 47 have heart defects; 280 are orthopedically handicapped with 182 wheelchair users; 63 are blind; 101 have a hearing impairment, 18 of those are deaf; 385 have no speech or speech impairment; 277 of the residents require feeding assistance; 310 need toileting assistance; 384 need help dressing; and 394 need help to bathe; 437 residents are not capable of making an appropriate response to an emergency; 375 require 24-hour awake supervision; 177 require physical therapy; 276 have behavior problems, and 142 of those are considered to have endangering behaviors.

Forty females and seventy-four males require psychoactive medication, and all of those are on behavior management programs. In addition, there are 66 others on behavior management programs.

The high standards that Medicaid imposes give the parents a real secure feeling that our children are properly cared for. But recently, HCFA—is imposing on these really fragile people so-called active treatment, which I was told by Matt's social service worker was not defined in writing but result in the staff actively engaging these people from 6 a.m. to 9 p.m.

Now I understand that this means that they cannot take a snooze or just sit and veg for a while like we all do occasionally.

Now HCFA is really putting these institutions through the wringer on this active treatment issue, and many people think that 15 hours a day is inhumane to some of these residents. And since no written definition has been proferred by HCFA, I wonder if it is just another rock to throw at institutions to undermine them, and to further chop away at their credibility.

Let me tell you that these folks in the institutions have a very faint voice. They are the most needy and the most dependent souls in this society. If you Senators phase down funding to these institutions, you will pull the rug out from under these Americans who need our help more than the drug addicts.

Expand the Medicaid program but let the States determine where and how to use it. Phase down the Medicaid funding and you will close the private residential centers. And in Nebraska, that means three Lutheran residential centers.

The States, especially rural States like Nebraska, may scale down their public facilities somewhat and keep them open on State general funds with much lower standards because of the lack of resources in the western two-thirds of our State.

Thank you very much.

Senator DURENBERGER. Thank you very much.

Senator DURENBERGER. Dana Kruse.

STATEMENT OF DANA KRUSE, SECOND VICE PRESIDENT, SICK KIDS NEED INVOLVED PEOPLE, "SKIP," INTERNATIONAL FALLS, MN

Ms. KRUSE. Thank you, Senator Durenberger.

My own child, Jennifer, is a special needs child, and I would like to tell you about her in order that you may have a better understanding of the problems that surround a disabled child and the critical need for increased support and planning.

Almost 4 years ago, when Jennifer was 2½ years old, a tragedy struck our family when Jennifer became a near drowning victim. She was revived, and through the miracles of modern medicine she has lived, but the disabilities caused from her accident are innumerable.

Jennifer suffered oxygen deprivation which caused massive brain damage, leaving her in a comatose state, unable to walk, to talk, or move her hands. Little did we know that life as we had known it—her running, laughing, and calling our names—was gone forever.

During the agonizing months that followed, Jennifer struggled to stay alive despite overwhelming odds. She became dependent on a ventilator to keep her alive. Bolts were drilled into her skull to monitor brain swelling, and a multitude of lines and tubes were inserted into her body to administer food and medication and to monitor her vital functions.

We waited, and we prayed for the time that Jennifer would wake up and start to improve. We looked to the experts for answers, for guidance, and for reassurance and found that it wasn't always there.

As Jennifer's condition began to stabilize, attempts were made to remove her from her life support. A tracheostomy was performed in an attempt to remove her from the ventilator and a permanent gastrostomy tube was inserted into her stomach for feeding.

What hope we had for total recovery soon faded during the rehabilitative period that followed, which included a total of 16 months and transfers to 4 different hospitals. She developed a severe seizure disorder, and in an attempt to control her seizures, radical medication therapy was initiated with devastating side effects. She developed muscle contractures and brittle bones, which ultimately led to the dislocation of both of her hips, fractures of both of her legs and a broken collarbone.

In her debilitative condition, she developed pneumonia and then chicken pox from which she nearly died. But Jennifer did survive, and she remains in a coma with little chance for recovery.

The life or death situation, the trauma and the rehab that our family went through seems like a century ago when, in fact, it was not much more than a year. It was at that time that the questions started, "What now? You are going to institutionalize her, aren't you?"

It was at this time that we, as consumers, were introduced to what we call the system.

Jennifer's health insurance funds were running low, and we were told that institution care would not only be the most economical but be the most humane for myself and my family. We were told we could put our lives back in order and get back to living again. But how could we forget the child that we love, knowing she would be taken care of by strangers in a place far away from our home? It didn't take us long to learn that we had to stand up for our rights, and in the midst of our grief we learned to humble our-self and ask for help from those who cared, and could make a difference.

We were successful after many legal battles to encourage our insurance company to agree to home care for Jenny. The savings and dollars were well documented, and we were able to decrease the cost by over 33 percent, and with the assurance of documentable quality care, we were on the road to getting our family back together again.

While Jennifer's story may seem to many of you almost inconceivable, believe me, it is not. The stories and lives of many of these special children are sadly and unfortunately very similar. But what happens when you run out of insurance? What happens when you run out of money? You aren't able to buy services. Are you once again faced with the institutional question: What happens when you as a family are seemingly put in situations where life and death decisions for your loved ones are based on dollars and established policy rather than medical appropriateness and dignity?

We quickly become the experts in services delivery, as well as the funding system, or our child will pay the highest price if we don't.

After numerous contacts with the Health and Human Services Division, we are told we are fortunate to live in one of the less than 30 States and territories that can cover the total care package that Jennifer will need. Now the question remains, How do we access this great program within the State of Minnesota? Do we get there by being eligible for the categorically needy program of Medicaid, or is that just for people who fall under the financial assistance category? Because both my husband and I work, it has only been the drain of Jennifer's medical expenses that wave put a financial burden on us. So if we do not quality for the categorically needy program, then are we eligible for the medically needy program?

Jennifer is certainly medically needy. But do we have to spend down to the poverty level to gain access for Jenny? But then there is the 2176 Waiver Program that services only a selected population in need.

After reams of rules and regulations that are so mind boggling and discouraging, you are ready to give up unless you become determined to sort your way through the maze. I am afraid that so many parents do just that and give up. Then what is there left for them?

Senator DURENBERGER. Thank you.

Ms. KRUSE. Thank you.

Senator DURENBERGER. We appreciate your testimony very much.

[The prepared written statements of Ms. Kruse and Ms. Barbara Konopka, president, Congress of Advocates For the Retarded, Inc., follow:]

SKIP, INC.
SICK KIDS (NEED) INVOLVED PEOPLE

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FINANCE SUBCOMMITTEE PUBLIC HEARING

MEDICAID FINANCING OF SERVICES FOR DEVELOPMENTALLY DISABLED PEOPLE

FRIDAY, SEPTEMBER 19, 1986

TESTIMONY GIVEN BY DANA J. KRUSE
PARENT AND 2ND VICE PRESIDENT OF SKIP NATIONAL

TESTIMONY WRITTEN BY KAREN A. SHANNON
PARENT/FOUNDER AND NATIONAL EXECUTIVE DIRECTOR OF SKIP NATIONAL

FINANCE SUBCOMMITTEE PUBLIC HEARING

MEDICAID FINANCING OF SERVICES FOR DEVELOPMENTALLY DISABLED PEOPLE
Friday, September 19, 1986

Testimony given by Dana J. Kruse
Parent and 2nd Vice President of SKIP
Testimony written by Karen A. Shannon
Founder and National Executive Director of SKIP, INC.

Good morning Senator Durenberger and other members of this distinguished committee. My name is Dana Kruse and I am here today from International Falls, MN. I appreciate the opportunity to testify this morning on behalf of my own daughter and also the thousands of other disabled children across the country.

The parents and families of these unfortunate children confront on a daily basis overwhelming, and often times devastating, personal circumstances surrounding their children. As different as each family and their situation is, they all have one thing in common, they are determined to create the best possible life for their child. However, due to the current lack of coordination of benefits and accessibility of services that are critical to the well-being of these children, many, if not all families, are experiencing enormous financial difficulties.

My own child, Jennifer, is a special needs child and I would like to tell you about her in order that you may have a better understanding of the problems that surround a disabled child and the critical need for increased support and planning.

Almost 4 years ago, when Jennifer was 2 1/2 years old, a tragedy struck our family when Jennifer became a near drowning victim. She was revived and through the "miracles of modern medicine" she lived, but the disabilities caused from the accident are innumerable. Jennifer suffered oxygen deprivation which caused massive brain damage leaving her in a comatose state; unable to walk, talk, or move her hands. Little did we know that her life as we had known it - running, laughing, calling out our names - was gone forever.

During the agonizing months that followed, Jennifer struggled to stay alive despite overwhelming odds. She became dependent on a ventilator to keep her alive, bolts were drilled into her head to monitor brain swelling and a multitude of lines and tubes were inserted into her body to administer food and medication and to monitor her vital functions.

We waited and prayed for the time that Jennifer would wake up and start to improve. We looked to the experts for the answers, for guidance, for reassurance and found it wasn't always there.

As Jennifer's condition began to stabilize, attempts were make to remove her from life support systems. A tracheostomy was performed in an attempt to remove her from the ventilator and a permanent gastrostomy tube was inserted into her stomach for feeding.

What hope we had for total recovery soon faced during the rehabilitative period that followed, which included a total of 16 months and transfers to 4 different hospital. She developed a severe seizure disorder and in an attempt to control the seizures,radical medication therapy was intiated with devastating side effects. She developed muscle contractures and brittle bones, which ultimately led to the dislocation of her hips and fractures of both legs and collarbones. In her debilitated condition, she developed pneumonia, then chicken pox, from which she nearly died.

But Jennifer did survive, however, and she remains in a coma with little chance for recovery.

That part of our families life seems like a century ago, when in fact it was not much more than a year. It was then that the questions started, " What now, you are planning to put her in an institution, aren't you?" It was at this time that we were introducted to what we as consumers call "the SYSTEM".

Jennifer's health insurance funds were running low and we were told that institutional care would not only be the most economical, but the most humane to myself and my family. We were told we could then put our lives in order and get back to living. But how could we forget the child we loved, knowing she would be taken care of by strangers in a place far away from home. It didn't take us long to learn to stand up for our rights for in the midst of our grief we learned to humble ourselves and ask for help from those who cared and could make the difference.

We were successful after many legal battles to encourage our insurance company to agree to home care for Jenny. The saving in dollars $ were well documentated, and we were able to decrease the cost by over 33% and with the assurance of documentable quality care, we were on the road to getting our family back together.

While Jennifer's story may seen to many of you almost inconceivable, believe me, it is not. The stories and lives of many of these "special children" are sadly and unfortunately very similar. But what happens when you run out of money? you aren't able to purchase services? are you once again faced with the institutional question? What happens when you as a family are seemingly put in situations where life and death decisions for our loved one are based on dollars and established policy rather than medical appropriateness and dignity? We quickly become the experts in the services delivery, as well as the funding system, or our child will pay the highest price if we don't.

After numerous contacts with the Health and Human Service Division we are told we were fortunate to live in one of less than the 30 states and territories that can cover the total care package that Jennifer will need. Now the question remains how do we access this great program within the state of MN? Do we get there by being eligible under the Categorically Needy Program of Medicaid? or is that just for people who fall under the financial assistance category; because both my husband and I work and it has only been the drain of Jennifer's medical expense that have put a financial burden on us. So if we don't qualify for the Categorically Needy Program then are we eligible for the Medically Needy Program? Jennifer is certainly medically needy, but do we have to spend down to the poverity level to gain access for Jenny? And then there is the 2176 Waiver program that services only a selected population in need.

After reams of rules and regulations that are so mind boggling and discouraging, you are ready to give up unless you become determined to sort your way through the maze. I'm afraid so many parents do just that, GIVE UP, and then what is left?

We as Americans are duty bound to respond to the needs of our children, and all our fellow Americans. Our American dream is founded in the belief that all people are created equal and that all Americans have the right to persue life, liberty and happiness. The charge I leave you with is not from just One MOM, but all the Mothers across our land, "Alone we stand defeated, but together what we can achieve will move montains, all it takes is recognizing we have a problem and the will to do something about it.

Thank you for the opportunity of testifying before you today.

CONGRESS OF ADVOCATES FOR THE RETARDED INC.

TO ADVANCE
"...the interests of mentally retarded persons in achieving appropriate education, housing, medical and other services."

446 BERNARDSTON ROAD • GREENFIELD, MA 01301 • (413) 773-5155

STATEMENT OF BARBARA KONOPKA, PRESIDENT
ON BEHALF OF
CONGRESS OF ADVOCATES FOR THE RETARDED, INC.

Prepared for Presentation
at
FINANCE SUBCOMMITTEE HEARING
ON MEDICAID FINANCING OF SERVICES
FOR DEVELOPMENTALLY DISABLED PERSONS

SEPTEMBER 19, 1986

PRESIDENT
MRS. BARBARA KONOPKA
VICE PRESIDENTS
[illegible]
SECRETARY
[illegible]
TREASURER
[illegible]

DIRECTORS
[illegible]

ADVISORY COUNCIL
[illegible]

MEDICAL ADVISORY BOARD
[illegible]

I am Barbara Konopka, President of Congress of Advocates for the Retarded, Inc., a national organization of parents, families and guardians, working for the advancement of all mentally retarded individuals. We represent "the parents' voice" in advocacy across America. All officers and directors of CAR are parents of retarded individuals. We work without compensation, have no paid staff and utilize no public funds.

Since becoming incorporated in 1980, CAR has strived to bring together parents, families and guardians of mentally retarded persons to begin again to build a self-representing force in advocacy for our loved ones who depend upon us to speak for their advancement and protection. We wish to bring a halt to our children being fair game for self-proclaimed experts, political opportunists and get-rich-quick operators who are cashing in big on the dollars spent to "improve" the lives of the mentally handicapped.

During the 1970s, civil rights activists, moving through the process of deinstitutionalization, intruded upon the lives of mentally retarded persons and their families to push forward as a national goal, a philosophy of freedom that has caused death, destruction and devastation to these individuals and families swept up in this ideological wave of social reform.

Mental retardation has become a megabucks business. "Community placement has grown from concept to program to ideology", stated one lawmaker a few years ago. "Every action, every appropriation, every policy is directed at shuffling people, not treating them." The situation remains the same today.

Parents of mentally retarded children and adults are in the center of the social reform arena and split apart by bureaucratic game playing in the movement to gain control of federal and state (program) dollars in order to perpetuate the mental retardation bureaucracy.

In the 1980s, the bureaucracy has become imbedded in the legislative process. At the federal level, the goal is to redirect Medicaid dollars away from residential centers of care and treatment of the most seriously impaired, a move planned to bring about the demise of this important part of a service continuum.

THE COMMUNITY AND FAMILY LIVING AMENDMENTS NOW SITTING IN COMMITTEES IN THE U.S. SENATE AND HOUSE OF REPRESENTATIVES (S.873 AND H.R. 2902) REPRESENT ATROCIOUS ASSAULTS AGAINST THE MOST SEVERELY AND PROFOUNDLY HANDICAPPED AMONG OUR RETARDED POPULATION.

Although this hearing has been described as "not a hearing on the Chafee bill", it was reasoned in announcement "to evaluate where and how the funds are being spent and whether services are being provided in the setting most appropriate to meet the needs of the individuals receiving services."

In the book of testimony presented on the Community and Family Living Amendments of 1983 (Hearing 98-775, held on February 27, 1984), Senator Durenberger stated in his closing remarks: "To go back to the focus of this hearing, for people who wanted to be witnesses today it looked like this was a hearing to say whether we were for or against S.2053, I have concluded this is a hearing that is for the disabled in America, and for the improvement in their health care."

"....I don't feel that we ought to be constrained by the $8 billion or the $4 billion, or whatever it is, dollars and say, 'There isn't enough to do this right,' because there is so much in other parts of the system that we are absolutely wasting, that we shouldn't use that to beat up on health care for disabled persons."

Whether or not settings are appropriate cannot be determined without the informed opinions of parents of the individuals being served. Appropriateness of settings should not be determined by the amount of dollars governments deem sufficient or are willing to spend. Neither should individual needs be determined by "what is available". This has been the case too long for too many. Such direction results in tissue-paper planning. Without utmost consideration and priority afforded parent/family/guardian judgment, individuals are ultimately ill-served and everyone loses.

Twenty years ago, the United States of America made a commitment to the mentally retarded of this nation. Through that commitment, much has been improved for many among our retarded population. For the severely and profoundly impaired, we have gone too far. "We've lost our sense of priorities", stated Elliot Richardson, former Secretary of Health, Education and Welfare, in an address before the President's Committee on Mental Retardation (May 11, 1986). "We need to refocus our minds on the questions, What can society afford to do on behalf of those who need our help? What can we afford not to do? Why cannot we afford to do as much today as five-ten years ago?"

"And what standards should apply to the level of quality of a civilization", asked Ambassador Richardson. "The best of all measures: Society's response to the least valued of its members."

The Mental Retardation Establishments

Excerpted from "Meeting the Needs of the Retarded" by Dr. Robert L. Isaacson,
State University of New York at Binghamton, New York

The groups of administrators who interpret, implement, and monitor programs for the mentally deficient exists nationally, within states, within regions of states, and within institutions. The group of professional administrators of prominence within a state are relatively few and known by people in similar positions throughout the country. Spokesmen for this group of nationally known administrators represent a powerful lobby on the national scene. They also are influential in the states they represent.

Within regions of a state and within institutions a similar situation exists. Certain of the higher administrators represent their institutions to the state leadership and to the community. Without intention, perhaps, they have assumed the role of spokesmen for the employees serving under them.

These establishments play an important role in the development of programs for the mentally deficient. They develop their own ideas and plans for the mentally deficient. These ideas and plans reflect a uniformity and cohesion that comes from discussion among the members and a subsequent agreement among those involved. They are presented by the articulate spokesmen of the several establishments to people and groups influential in the legislative processes. They have access to those who have the decisionmaking power in government.

Many of the professional administrators are active or influential in national, statewide, and local groups organized to support the cause of the mentally deficient. These are associations which were established initially by parents to function as political lobbies. Typically, these organizations become so large that they must be run as businesses by professional administrators who have strong identification with other professional administrators in the state and federal bureaucracies.

As with many such groups, a minority of the members come to exert disproportionate influence. These are people with personal energy and drive. They are appointed to committees, become committee chairpersons and elected officials. The majority of the members do not become active participants. Since parents of mentally deficient persons come from all walks of life, a substantial number are far less educated than the professional administrators who become authority figures. In many instances, the opinions of the administrators are accepted unquestioningly by individual parents and parent groups.

In effect there are two major voices that influence the political scene: the establishments made up of the professional administrators and establishments composed of parents and similar groups who champion the cause of the mentally deficient.

While society, the public at large, may have views about the care and treatment of people with mental deficiencies, these are ill-formed and vague. Seldom are they expressed directly to those people and agencies that make decisions. Instead, it is the views of the mental retardation establishments that are made known to the decision makers. These views may or may not represent those held by the public-at-large or even by the majority of members of the bureaucracy. They may not even represent the feelings of parents in parent-groups since, as we noted above, the official opinions are forged by the few leaders of the groups.

The leaders of the various mental retardation establishments hold views that may not be those of their constituents. For those in the state and federal bureaucratic establishments, the constituents would be the employees of the government agencies involved with the care and treatment of the mentally handicapped. The needs of these public employees should be represented, but they are not identical with the needs of the mentally deficient themselves. In principle, the parent groups would seem to be the most likely bodies to represent the needs of the mentally deficient. However, as mentioned, some of these parent groups have their opinions shaped by a minority who are leaders and professional administrators. Fads and trends in care and treatment may be established because of the politically active and vocal groups in the establishments. Only when there are wide discrepancies between current practices and views of society will there be a major "correction"......

Senator **Durenberger**. John, do you have a question?

Senator **Chafee**. Well thank you very much, each of the witnesses. I have had the privilege of hearing from being associated with some of you before.

I do want to say to Miss Crawford that in connection with the legislation that I have sponsored, we have a set aside for those States that wish to use institutions, and I think it is important that that be recognized.

The testimony we have had from Mrs. Kruse, and Dee Everitt, and others, I particularly want to congratulate Jeff Gunderson for his testimony. I understand this is your first visit to Washington, the first time in an airplane.

Mr. **Gunderson**. This is the first time I have been out of the State in 17 years, except to see my sister in Illinois.

Senator **Durenberger**. That is why they have got the bumper sticker that says "Escaped from Wisconsin," right? [Laughter.]

I had to get that one in, Jeff.

Mr. **Gunderson**. In this case, I think that is true. [Laughter.]

Senator **Chafee**. So we want to thank each of you. Your testimony has been very, very impressive, and helpful and moving. Thank you.

Senator **Durenberger**. Jim.

Senator **Exon**. I want to thank all of you for your testimony. I was called out for just a moment.

Jeff, I listened to your testimony very carefully, and I want to congratulate you for being here today. Your testimony was tremendously important.

Mr. **Gunderson**. Thank you.

Senator **Exon**. It gives us an insight, and I really believe that the insight that we get from you is a case in point for community based programs, and programs outside of institutionalization.

Dee, I thank you for your testimony. Miss Kruse, I had to be called out and I missed yours.

Pat, thank you for your testimony. Pat Crawford, I think, is carrying on a concern that we legitimately have for not only the Jeffs of the world, where the community based program and noninstitutional care has been a great plus, but there are others.

John, I am glad to see that you have something in your bill about exempting States, and I will be glad to talk to you and maybe we can work that out.

I simply want to say that I hope we do not get down into the customary battle that we seem to get into on these issues by recognizing—I emphasize once again—the very needs of the various people that we are trying to help. Taking away from one and giving to another, in my opinion, is not the answer, because when we do that we forget those who cannot come here and testify and speak. There are other. [Applause.]

Senator **Exon**. Therefore, I simply say that let's approach this with caution.

I emphasize once again, Mr. Chairman, as I think both Dee and Pat Crawford know very well, I am a strong supporter of both. What we come down to is where are we going to get the money from to take care of both? It is an obligation we all have and let's continue to work on it.

Thank you all for being here.

Senator **Durenberger**. Let me just very quickly summarize and end the hearing by saying that on the point Jim made at the end, where is the money going to come from, that I think you don't have to be here too long to understand that this Nation—I made this little talk yesterday to a group of Mongs, and Laosians, and Cambodians and Thais who were afraid that their families would never come to this country, for example, because we don't have enough money. The reality is that this is a very rich nation in many, many ways. The resources are all out there. The financial resources are there and the human resources are there. Sometimes it is just simple utilization of TLC and that sort of thing.

But as Lowell Weicker said, I think, in the beginning, and as John Chafee said in his opening remarks, it is a question of how well can public policy, particularly in the financing of services, keep up with what is actually going on in the community? Some of that is technological, but a whole lot of it is in the parents here, for example, who have been testifying today, in their view of their own capabilities and the capabilities of the community around them, and how that has changed and changes over a period of time. Are we, the challengers, going to be able to be capable of formulating policy changes that can adapt to the realities of what is going on in the world?

The resource issue I don't think is a problem. I think the resources are there. But the current public policy makes it very difficult for us to put the right resources in the right place to do the right thing at the right time.

So I will just end again by saluting my colleague here on my right, John Chafee, for his leadership over the years on this issue. My sense is that, as you indicated in your opening statement, that in the next Congress, as we come to grips with the various elements of so-called welfare reform, as they call it around here, catastrophic insurance, what are we going to do about the chronically ill, the issues of long-term care for the disabled and for the elderly, are all on the President's platform. I think in this committee, in 1987, you will see us come to grips with the challenge that John Chafee has laid out here for us over the years. All of these hearings, and all of these places with all of these peple, and all of this emotional charge, if you will, will have been fruitful.

On behalf of all the other members of the committee who could not be here, let me express my appreciation to those of you who are here representing hundreds of people who cannot be here today.

Thank you for being here.

Senator **Chafee**. Mr. Chairman, I would just like to say one thing. First of all, we want to thank you for your continued interest and involvement in this effort. You have been excellent in your leadership—we all appreciate it—as chairman of this subcommittee.

Second, I would hope as we leave that we bear in mind what Dee Everitt said. We are not just dealing with institutions or community living or the facilities or Medicaid, we are dealing with human beings. Those are the people I think we have got to keep in mind as we wrestle with these problems.

Thank you very much.

Senator **Durenberger**. John, thank you. Ladies and gentlemen, we thank you. The hearing is adjourned.

[Whereupon, at 12:53 p.m., the hearing was concluded.]

[By direction of the chairman the following communications were made a part of the hearing record:]

ahca
American Health Care Association 1200 15th Street, Washington, DC 20005 (202) 833-2050

The American Health Care Association is the nation's largest federation of long term care facilities. Over 9,000 member facilities provide care to chronically ill and developmentally disabled of all ages. AHCA commends the Senate Finance Committee for conducting these hearings on the issues of Medicaid funding for services for the developmentally disabled and appreciates the opportunity to provide comments on them. AHCA believes that a wide spectrum of institutional and noninstitutional services must be funded if the needs of the developmentally disabled are to be addressed.

BACKGROUND

In 1972 Congress extended Medicaid coverage to include intermediate care facilities for the mentally retarded (ICFs/MR). Active treatment and 24-hour supervision are required for certification. Current rules to implement the program are being revised for final publication in 1987. The goal of the ICF/MR program is to help each developmentally disabled person reach his/her maximum potential. Each resident must have an individual active treatment and training program. Active treatment is a planned, goal-oriented therapy program which assumes the resident can develop beyond current capabilities.

Under the Medicaid rules, ICF/MR facilities are licensed and monitored by states. Currently, 560 specific federal standards govern ICF/MR facilities. In addition there are state standards. Facilities are inspected annually to determine compliance with the standards.

The ICF/MR program serves persons with a broad range of disabilities, such as blindness, cerebral palsy, epilepsy, and mental retardation. Professional services offered to residents include nursing, dental, medical, psychology, physical therapy, occupational therapy, speech pathology, audiology, therapeutic recreation, pharmacy, social and dietary services. These services, in addition to room and board, comprise the "total" care the ICF/MR facility must provide.

Most developmentally disabled persons are cared for by their families in the home and receive services through health, education and training programs. Other developmentally disabled are cared for in ICF/MR facilities. Six to fifteen percent of all mentally retarded live in some form of supervised residential setting such as state institutions, private ICFs/MR, and foster care or small community facilities. The most severly handicapped individuals are cared for in the large public and private institutions. A 1982 study, "Classification of Residential Facilities for Mentally Retarded People," found that 19 percent of the populations of large private institutions are profoundly retarded and 14 percent are nonambulatory. The profoundly retarded are only 10 percent of the populations of small group residences and only 5 percent are nonambulatory.

A non-profit organization of proprietary and non-proprietary long term health care facilities dedicated to improving health care of the convalescent and chronically ill of all ages. An equal opportunity employer.

At the present time a state has the option to operate an ICF/MR program. Some state Medicaid programs support only state institutions and community programs; however, others support a variety of programs, including mid-sized private for profit and non profit facilities. In the last decade, a trend toward developing community care facilities has developed. For example, over the last decade the total population of large state institutions has declined by one-third while the number of community care programs has increased ninefold. New admissions to supervised apartments during 1982 increased by 32 percent while new admissions to large facilities grew by only 6 percent. One-third of the existing small programs have opened since 1980.

AHCA POSITION ON CARE OF THE DEVELOPMENTALLY DISABLED

CONTINUUM OF CARE IS NEEDED

AHCA supports a wide spectrum of services for the developmentally disabled and advocates a system which provides service delivery in settings tailored to address the needs of the individual. AHCA opposes proposals to limit reimbursement for services to a single model of service delivery. The needs of the developmentally disabled are diverse and must be addressed by a variety of systems and programs. Clearly a mildly retarded, ambulatory, verbal individual needs a level of care that is different from the care needed by a profoundly retarded, nonverbal, nonambulatory person.

For some developmentally disabled persons a small facility may be ideal. For others, especially those with numerous, complex needs, a larger facility than can offer an array of services and full staffing is more appropriate. For still others, there will be a need for different levels of care as developmental and functional skills change. If all facilities are limited in size, no single facility will be able to provide a wide array of services. This will cause particular problems for the severely handicapped who need continuous multiple services such as professional nursing services, physical therapy and occupational therapy on a daily basis.

REIMBURSEMENT AND THE CONTINUUM

Studies supporting the theory that small, community-based facilities are less expensive than institutional care can be misleading. In order to correctly interpret them one must understand the various types of institutional and non-institutional care provided for ICF/MR clients and the reimbursement systems which fund them.

Two types of facilities comprise "institutional care facilities." This fact is not usually apparent in cost studies which label institutional care as the most expensive. There are large state facilities and there are private ICF/MR facilities, such as those which are AHCA members. Large state owned and operated facilities are the most costly. In part, this is because of higher labor and property costs and the higher costs associated with the heavy care clients for whom they provide care. Full cost reimbursement through Medicaid results in payment of over $100 per day per resident in many state institutions. AHCA member facilities are private proprietary and nonproprietary facilities which range in size from 16 beds to 200 beds but average approximately 70 beds. Private facilities are reimbursed per diem rates of approximately $50 to $65 dollars per day per resident.

AHCA hopes that the Committee will focus on the cost of providing appropriate services for each client before it concludes that one model is less expensive than another. This is important because the total cost of care is not always reflected in the Medicaid per diem reimbursement. Small (up to 15 beds) facilities utilize training, education, transportation, social services, and therapy programs which are supported through state and county governments, United Way and charitable donations. Many of the residents also are SSI beneficiaries. The costs of these services are not included in the daily rate that is funded through Medicaid. Mid-size and large facilities usually provide comprehensive services on campus as part of the facilities' program. The costs of these comprehensive services are included in the Medicaid per diem rate.

Medicaid funds both institutional and noninstitutional services for the developmentally disabled. Medicaid funds the institutions which meet the ICF/MR standards described earlier. Medicaid also funds services for the developmentally disabled through the Sec. 2176 Home and Community Based Services waiver program for individuals who would otherwise be institutionalized. In addition, the recently enacted Sec. 9516 of the Consolidated Budget Reconciliation Act provides the state Medicaid agency with options to either approve six month plans of corrections for deficient facilities or plans to reduce permanently the population of the facility by moving clients to community services.

AHCA POSITION ON CURRENT PROPOSALS

There are several proposals before Congress which would alter Medicaid financing by directing substantially all Medicaid funding to a community-based model of care. AHCA opposed these proposals because they would limit the availability of services for the developmentally disabled to the community care model and prohibit access to Medicaid funded institutional care.

One of these proposals, S. 873, the Community and Family Living Amendments, would restructure Medicaid services for mentally retarded and other severely disabled individuals. S. 873 proposes to phase out most funding for institutions and shift it to the community-based services over 14 years.

AHCA's objections to S. 873 are centered on the following major points:

- Not all severely disabled persons can be cared for in community settings.
  - Many severely disabled are physically and mentally handicapped and suffer from life-threatening medical conditions. Some are frail and need constant observation by professional staff. A recently published article in the October 1986 American Journal for Public Health noted that several medical specialties essential to the care of deinstitutionalizeds individual in Massachusetts were not available in the community.

-- A large portion of institutionalized mentally retarded residents also suffer from serious behavioral problems. These people require a high staff ratio and intense care by trained individuals. Access to professional help is a necessity for both staff and residents. Experience shows that these clients are the most difficult to place in community care, and are the most likely to fail in small community settings and return to the institutions.

-- Some past deinstitutionalization of the severely disabled people have failed miserably. Many believe that recent efforts in Kentucky and Florida resulted in examples of inadequate care, high mortality rates and irreversible damage to residents.

o Quality is not directly related to size.

-- Larger facilities can provide more services and can develop a professional staff to deliver varied and complex sophisticated services. Because of the nature of the funding source for large facilities, clients are less dependent upon varied and categorical program appropriations which can be changed or terminated. Such changes can disrupt or cancel services.

-- Numerous studies have concluded that size is not related to quality of care, that homelike facilities do not guarantee improvement, and that family style homes can be more restrictive than larger settings.

-- In larger facilities residents engage in more social behavior and develop more friendships than residents of small facilities, as found in at least one study comparing small and large settings .

-- Larger facilities, by virtue of large professional staffs and large numbers of visitors, allow for greater opportunity to formally and informally monitor resident care.

-- The life safety of disabled people is enhanced through physical structures built or modified to meet life safety and other code requirements developed to provide needed protection. Family homes are not designed to provide this protection.

o Mandating community care for all severely disabled persons will increase the cost of care.

-- The total cost of care: room, board, services, training, medical care, transportation of community care clients, can exceed the cost of private ICF/MR care. For example, in 1982 the cost of small group residences with day programs was $62.70. The cost of large private ICF/MR care with day programs was $56.83.

-- Additional costs which would result from community care models:

1. Additional costs of administering, monitoring, surveying and inspecting a greater number of facilities scattered

throughout the country.

2. "Start up" costs which would be associated with the program. These should include the cost of maintaining the empty beds at the large facility. Costs are associated with the additional number of staff who will be needed to compensate for time lost traveling to, from, and between many small facilities. Labor costs are approximately two-thirds of the program costs.

3. Costs of deinstitutionalizing the heavy care resident. Approximately one-fifth of the residents of private large institutions and over one-half of those in public facilities are profoundly retarded. Fourteen and 25 percent of the institutionalized are nonambulatory. Most community care programs care for more able persons, less than 10 percent are profoundly retarded and less than 6 percent are nonambulatory. The greater the disability, the greater the need for staff and the greater the cost of care.

A second proposal, S. 1948, the Quality Services for Disabled Individuals Act, would establish a Bureau of Quality Services in HHS, require surveyor training and standards for residential facilities and require the state to establish a home- and community-based services program for persons who would otherwise be institutionalized at a greater cost. AHCA has no major objections to this proposal as it pertains to the developmentally disabled. AHCA supports the concepts in the legislation which require state plans for screening, appropriate levels of care criteria and a strategy for developing home- and community-based services.

AHCA RECOMMENDATIONS

AHCA believes that Medicaid funding of services for the developmentally disabled could be enhanced by making the Sec. 2176 Home and Community Based Services Program permanent instead of a program which sunsets at regular intervals. State planning for home and community services involves training staff, construction or substantial renovation of residences, screening and assessing individuals and other long range functions which are difficult when the funding source may be temporary. With the exception of the sunset provision, the Sec. 2176 program allows states to provide a wide variety of services. Congress should consider removing this one barrier.

Any changes in Medicaid must encourage a balanced approach to the care of the severely disabled. The severely disabled are a heterogeneous group and cannot be cared for in a narrowly designed system which works under certain circumstances.

There is a need for small facilities, respite care, day programs and the entire continuum, including institutions. Those who can be adequately and efficiently cared for in small facilities should have the option to reside in them. Unfortunately, many people are unable to develop the skills necessary to live in small group homes. These people may be profoundly retarded, blind, crippled and suffering from any number of medical conditions. These people need nursing, therapy and custodial care 24-hours a day in addition to training. Is it practical or even possible to provide these services in small scattered settings? Even if the personnel were available, the cost would be prohibitive. The total cost of a nursing visit, a home health aide visit and a therapist visit could be as high as $80 per day. Add to this the cost of room, board and custodial care and the total cost is much more than what Medicaid now provides.

We support the goal of independence; however, the developmentally disabled need and deserve more than a system which is based on an arbitrary number of beds, not the quality of services.

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EXECUTIVE DIRECTOR
James H. Rummel

September 22, 1986

Betty Scott-Boom
Committee on Finance SD-219
Dirksen Senate Office Building
Washington, D.C. 20510

Dear Ms. Scott-Boom:

We wish to offer the following written statement to the record of the September 19 Senate Finance Committee Subcommittee on Health hearing on Medicaid financing:

In Minnesota, Medicaid policies have dictated service development. Therefore to a great extent, the only service that has been developed to meet the long-term care needs of people with developmental disabilities has been Intermediate Care Facilities/Mental Retardation (ICF/MR). Over 7,000 ICF/MR beds currently are licensed in Minnesota.

Alternative services, especially family supports and long-term care services in less restrictive settings, have been in great demand. It was not, however, until Minnesosta began utilizing the Title 19 Home and Community Based Waiver that these services became available. The ARC has seen the demand and preference for these services grow considerably over the last two years. In addition, their availability is enabling four large facilities (40 - 100+ beds) to close down and place people in smaller and more appropriate settings.

In Minnesota at least, Medicaid policies have a profound impact on the development of our service system. This is why ARC Minnesota so strongly supports the Community and Family Living Amendments. It will enable us to meet the demand for small community services and continue to phase down and close larger institutional programs. ARC Minnesota strongly believes that all people, regardless of the severity of their disability, can live in small community settings provided that community supports exist. Due to the impact Medicaid has on long-term care services, we believe that its policies should be promoting the use of small community based services which most appropriately meet the needs of people with developmental disabilities.

We sincerely hope the committee will carefully examine the issues regarding long-term care prior to and in conjunction with consideration of any proposed solutions, including the Community and Family Living Amendments.

If we can be of any assistance in clarifying the issues in Minnesota or providing you with additional information, please do not hesitate to contact us.

Sincerely,

Betty Hubbard

Betty Hubbard
President

BH/cm

TESTIMONY ON MEDICAID FINANCING OF SERVICES FOR DEVELOPMENTALLY DISABLED PERSONS

By ALEXANDER L. NAPOLITANO, EXECUTIVE DIRECTOR
On behalf of BETHESDA LUTHERAN HOME
Watertown, Wisconsin 53094

Prepared for the September 19, 1986, Hearing
Held by the Subcommittee on Health of the U.S. Senate Committee on Finance

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Thank you for this opportunity to share suggestions regarding Medicaid funding of services and long-term care for developmentally disabled persons. We are concerned because some of the approaches which have been proposed have had the effect of splitting the ranks of advocates for persons with mental retardation. It is essential that all who have an interest in their care (including parents, providers, legislators and retarded individuals themselves) work together to improve, assure and fund a full spectrum of education and services. We believe this hearing is an excellent step in that direction and hope that future discussions will expand opportunities for verbal .nput from a much broader segment of those who are concerned.

I. BETHESDA'S EXPERIENCE

Since 1904, Bethesda Lutheran Home has served over 2,600 retarded children and adults, earning a nationwide reputation for excellence in the field. Currently we serve over 450 retarded individuals from 31 states and one foreign country on our main campus in Watertown, Wisconsin. This represents a voluntary reduction from a high of 660 beds 10 years ago. We also operate 14 group homes in nine states and Faith Village, a 65-bed cottage and group home complex in Shawnee Mission, KS, giving us a total of 650 residents in Bethesda facilities.

In addition, we are converting a beautiful eight-plex apartment building to supervised apartments in a Milwaukee suburb. We are also developing a cluster of three 15-bed units in Aurora, Illinois, and have just purchased two more sites for community living facilities in the Greater St. Louis, MO, area.

Bethesda employs a staff of 650 people, including doctors, nurses, therapists (occupational, physical, speech, recreation and music), psychiatrists, psychologists, residential aides, chaplains, teachers, social workers, a pharmacist, medical technologist, librarians, and a volunteer coordinator (who works with more than 5,000 volunteers who befriend, chaperone, assist and provide special entertainment for our residents, donating over 70,000 hours each year).

To provide information on services, facilities and materials, Bethesda operates a National Christian Resource Center. To provide consultation and prognosis for the future, we have a Diagnostic and Evaluation Center. We also publish curriculum materials, which we make available free of charge or at cost, and training and planning helps such as our new "Task Analysis." In addition, our Outreach Program provides seminars and workshops to train workers and encourages parishes to welcome and involve retarded people in congregational activities.

Our newest venture is an interactive video studio (scheduled for completion in December on our Watertown campus) where we will test new methods of training community living staff, teaching retarded individuals and doing medical diagnosis.

Our goal is to help retarded individuals develop their talents and abilities to their fullest potential, thereby enabling them whenever possible to live satisfying and productive lives in the community.

II. RECOMMENDATIONS

Based on our background and experience, we believe the following four points are essential to the provision of adequate, appropriate care and training for developmentally disabled individuals and should be the basis of any legislation that is approved.

A. An individual habilitation plan should be developed for every retarded person in need of services.

Benefits:

1. These plans will identify the services most needed by each

individual and outline a program for achieving the individual's maximum potential.

2. Cost effectiveness will ensue with more efficient use of services. These habilitation plans can become the guideline for establishing necessary services; current research is inadequate to determine precisely what additional services are required, how many group homes/foster homes, etc. are needed.

Guidelines:

1. Parents/guardians/advocates and clients should be involved with professionals in development of the plan.

a. Providers of services to developmentally disabled individuals must have an individualized program plan for each client and must be accountable for providing active treatment.

b. Each state should establish an identification and screening process for all developmentally disabled individuals who are potentially eligible for services.

2. The goal of each plan should be:

a. To help the retarded individual live as normal a life as can realistically be deemed possible and logical, given the individual's mental capacity and functioning level. Although all of life involves risk (and risk can be beneficial), nevertheless planning considerations should include:

(1) Safety/medical needs,

(2) Quality of life,

(3) Involvement in true community (which may or may not be the least restrictive setting),

(4) Client satisfaction,

(5) Maximum exposure to quality training techniques,

(6) An environment conducive to acceptance and respect of the individual. Mentally handicapped persons are not really free just

because they reside outside the four walls of an institution. Simply living in a house in a community does not assure quality of life and integration. It requires being wanted, involved, and accepted for your individual self-worth.

b. To prepare individuals who remain in the family home for the day when their parents, either because of illness or death, can no longer care for them.

B. Legislation should encourage, not limit a full spectrum of services, ranging from institutional care to supervised apartments and family living arrangements.

Benefits:

1. Availability of a comprehensive array of services:

a. Preserves freedom of choice for the retarded individual and his/her family,

b. Recognizes the fact that it is "normal" for most young adults to leave home for education and training (in large colleges and schools where they often live in dormitory settings) or for jobs,

c. Provides options for retarded adults whose families are overly protective or who are subjected to stress through family expectations that are too high.

d. Allows retarded persons to CHOOSE a cluster or private community (institutional/residential) setting just as golden agers CHOOSE to live in a senior citizen citizen complex.

e. Recognizes the individuality of each retarded person and allows them to progress at their own pace, rather than limiting the length of time they may remain in a facility where they are comfortable, happy and receiving appropriate care and training.

2. A full array of services (including both private and public agencies) not only offers options to the clients but also encourages competition among providers, thereby promoting improved services and

enhancing opportunities for clients.

Guidelines:

1. Service providers should be measured by quality (see item "C") and cost effectiveness, not by artificial or arbitrary size limitations. There is absolutely no proof that "big" is ALWAYS "bad" and "small" is ALAYS "good." Both have their benefits and both have their weaknesses and dangers.

2. Cost effectiveness should be determined by comparing apples with apples.

a. Provision of like services (at least for severely and profoundly retarded individuals) is normally less expensive and more efficiently done in a good institution or cluster than in a group home when all factors (residential services, medical and psychological care, education, training, transportation and inspection) are measured.

b. Carefully planned deinstitutionalization is desirable for higher level retarded persons, but a good institution or cluster can provide a more secure and beneficial environment for those who are medically fragile, who have behavior problems, and/or who are elderly and have mental or physical disabilities. For such individuals, a good private institution can also be the most cost effective, especially if it is a non-profit organization. PLEASE NOTE: Our statements in support of institutions should not be interpreted as favoring huge, isolated facilities of the 1,000 bed variety. We simply believe some people are better and more appropriately and economically served in an institution where all required therapies and services are readily and constantly available. In these facilities, quality - not size - should be the evaluating factor.

3. Emphasis should be on assuring true community (integration, satisfaction and friendship) - not simply on living IN the community. Larger facilities, in many cases, can offer a greater sense of community for the individual. As more and more people have moved into community settings,

we have seen more and more examples of isolation and loneliness, of inappropriate seeking of companionship and recreation, and of people unprepared to handle their new freedom. Therefore they often end up in the police system, on welfare roles or on the street.

Self worth may be fostered to a greater degree for some individuals in an institutional setting where they have a chance to "win" in competition with other handicapped persons, rather than always being the loser, the subject of stares and ostracism, the one who is left out because of inability to communicate or actively participate in favorite neighborhood pastimes.

Other shortcomings of the community setting for lower functioning, unprepared and/or disabled individuals may include: less intensive and less varied treatment opportunities, greater possibility of abuse, and, for the medically fragile, more restrictive living (confinement to a few rooms as compared with the vast expanse and opportunities of a good, large facility).

C. Quality should be assured through continuance of federal inspections, and these inspections should include all providers on a regular basis.

Benefits:

1. Federal inspection prevents states from having two standards - one for state facilities and another for private facilities.

2. Federal inspection protects residents' rights to have adequate services.

Guidelines:

1. Such inspections should place the emphasis where it belongs - on quality of services and provision of active treatment, rather than on size of provider.

2. Deemed status should be offered to facilities which achieve JCAH or ACMRDD accreditation. If an institution chooses to apply for the most stringent accreditation process - and achieves it - that should be adequate. Tax money could certainly be saved by not having to monitor such facilities.

3. All facilities, except those which achieve professional accreditation, should be inspected annually, regardless of size. There is as much potential for abuse and neglect in a small facility as in a large one.

D. Funding should be based on individual need and, like Medicare and standard medical insurance, should allow the person to choose where approved services will be purchased, without regard to county, region or state.

Benefits:

1. Such an approach preserves freedom of choice for retarded individuals and their families. Given the multiple syndromes, behaviors, and causes involved in retardation (with many still unknown), no single geographic area can provide all the services which are required.

People must be able to seek out services, even go across state boundaries if necessary to obtain the desired training and services. If this is not permitted, people will fall through the cracks right and left - in fact, this is already happening due to state allocation of funds through counties or regions. Just as a person with a disease travels to hospitals and doctors who specialize in the treatment of that disease in other states, so retarded people must also be given the ability to seek the services which their condition mandates, whether that means traveling within the state or across state lines. It is imperative that regulations regarding medical assistance funding be amended to allow this to be done. Once needs are determined, the money should follow the person.

2. Such an approach permits the exercise of religious preference. Freedom of worship is a basic of the American way of life. Too often no religious education is available to retarded people in the local community, and they must seek it elsewhere. Although facilities like Bethesda are working to help parishes reach out and involve retarded citizens in the local congregation, it may be years before all churches offer appropriate opportunities to developmentally disabled persons. Until that time,

retarded individuals must not be deprived of their right to worship and grow in faith. Habilitation plans and funding options must respect that right and allow religious instruction to be a consideration in the choice of placement.

3. Such an approach will reduce costs - the free enterprise system normally brings costs down and improves quality. People will patronize the best and avoid the worst, forcing them out of business. This approach has proven effective in British Columbia; their method should be tried in the U.S. Without such a provision, only those with adequate financial resources will be able to afford good private care of their choice.

Guidelines:

1. Habilitation plans should establish service needs and thus determine the approved funding level for each individual, based on federal funding standards. Plans should be reviewed annually.

2. A voucher system can enable the individual to purchase needed services in a facility/agency of choice.

3. Parental ability to pay should be a determining factor for those who are 18 years and under.

III. REACTION TO PENDING LEGISLATION

We applaud the primary intent of S. 873, which is to provide additional services for a greater number of mentally retarded people. We have experienced the frustration of families in Florida and other states who want and need services for their retarded relative, only to be told there are no more workshop openings and no monies available for more group homes or community services.

However, we strenuously object to the proposed CFLA method of extending services: namely, by eliminating or greatly reducing all or most of the institutions which serve developmentally disabled persons in the United States.

While we recognize that there is a limit to how far tax monies will stretch and to what Congress will approve for services in any area of need, it must also be remembered that government exists to do for people that which they cannot do for themselves. It has been our experience in raising funds for Bethesda that the general public readily sees and understands the need for services to retarded persons and is willing to expend money for this purpose.

Therefore, we believe that the "rob Peter to pay Paul" approach of S. 873 does an injustice to the American people through its supposition that the only way to obtain funds for services to retarded individuals is to take it from those who are in institutions. Moreover, as was indicated in our introduction, this approach has fractured the ranks of the advocates of retarded people at a time when unity, not infighting, is essential if progress is to be made.

To move forward, we must begin with better research, both in regard to needs and prevention. To achieve this, we must have a more concentrated and coordinated federal effort. Perhaps this can only be acomplished through the establishment of a new federal bureau, such as Senator Lowell Weicker proposes in his "Quality Services for Disabled Individuals Act of 1985" - S. 1948. His bill extends the Medicaid Waiver, thus encouraging continued innovative efforts in community services, while at the same time avoiding the pitfall of residential size limitations which is so controversial.

IV. IN SUMMARY

While Medicaid costs for services to developmentally disabled individuals have grown tremendously in the last decade, we must remember the reasons: the deinstitutionalization process has moved most mild and moderately retarded persons to less restrictive settings. Those who remain in institutions are primarily the severely and profoundly retarded, the elderly, the medically fragile and the dually diagnosed. To provide adequate care and active treatment for these persons, the good institutions (and there are many in this country doing an excellent job) have drastically increased their staffs - and inflation has also taken its toll.

Obviously this increases the cost of care - but no more, and in some instances less, than it would cost to provide the SAME services in a community setting.

And it's worth it when one see the progress of someone like Steve, born severely retarded and without eyes. For the first 12 years of his life, he was cared for at home by his devoted parents, who took him from doctor to doctor seeking help. All the consultants saw no future for Steve. Finally in desperation, his family brought him to Bethesda...a child who looked like a tiny infant, still drinking from a baby bottle. (His foster grandmother here used to take him for rides in a baby stroller!) In just a few years of loving care and training at Bethesda, Steve has grown to normal height, discarded his bottle, learned to feed himself solid foods, and learned to walk, run - and even rollerskate.

That's why Medicaid must continue to fund QUALITY care for developmentally disabled people...both in institutions and in community settings. That's why government exists - to help those who cannot help themselves.

CABINET FOR HUMAN RESOURCES
COMMONWEALTH OF KENTUCKY
FRANKFORT, KENTUCKY 40621

DEPARTMENT FOR MENTAL HEALTH AND
MENTAL RETARDATION SERVICES
An Equal Opportunity Employer - M/F/H

September 15, 1986

Ms. Betty Scott-Boom
Committee on Finance
Room SD-219
Dirksen Senate Office Building
Washington, D.C. 20510

Dear Ms. Scott-Boom:

As suggested in the press release No. 86-070, Kentucky's Department of Mental Health/Mental Retardation desires to present our view on the impact the Medicaid program has on the long term care of the developmentally disabled.

Your inclusion of this report in the printed record of the scheduled hearing will be appreciated.

Sincerely,

Dennis D. Boyd

Dennis D. Boyd
Commissioner

For the third year of our Medicaid waiver program (4-1-85 through 3-31-86), we served only 539 individuals reflecting a need for an additional 1,185 slots, based on our estimated need.

The following table reflects the number of unduplicated clients served and cost per recipient from both the institutional and community settings for the first three years of the waiver program.

ICF			Waiver Program	
Year	Clients	Costs	Clients	Costs
1983-84	1,369	$24,913	234	$ 6,457*
1984-85	1,260	$30,995	487	$18,167
1985-86	1,270	$30,724	539	$16,974

From the above data, it is quite evident that the Medicaid waiver program is very cost effective. The development of the estimated additional needed services is contingent on the continued availability of medicaid funds. The Kentucky Department of Mental Health/Mental Retardation solicits your endorsement of continued funding for ICF/MR facilities and increased funding for these community programs.

*The average annual Medicaid payment per recipient of AIS/MR waiver services is lower than projected due to a claims backlog. This backlog results from Kentucky's acquisition of a fiscal agent for Medicaid claims processing on July 1, 1983, which necessitated a development and transition period. Even if all recipients had received a full year of service when entered into the formula this figure would also show a savings.

Due to the claims delay, the second year of the project evidences artificially higher rates of payment per recipient. Therefore, the project would be most properly evaluated if the two years were combined.

In an effort to determine the need for residential beds, the State of Kentucky has utilized the methodology, developed by Dr. Michael Hogan, Deputy Commissioner for Mental Retardation for the State of Massachusetts. This planning methodology recognizes that a state cannot provide services to everyone who might qualify, but realistically plans to meet the needs of those individuals who are in real need of appropriate services at any time within a fiscal year.

Based on our population figures supplied by a publication of the Department of Commerce, Kentucky Economic Statistics, the following information represents the estimated need for services by service category of the population who is mentally retarded.

Category	Definition	Estimated Number of Persons
Independent Living	Individuals who are able to live without our services.	13,031
Minimum Supervision	Individuals with self-help skills, but who need periodic support with community living.	3,414
Moderate Supervision	Individuals who have basic self-help skills but need regular support and training in managing around their home.	1,199
Supervised Training	Individuals who require on-site supervision with training in self-help skills. (This category constitutes the medicaid waiver MR/DD population)	1,724
Supervised Living	Individuals who require intense on-site supervision and considerable to total assistance in self-help skills. (This category constitutes the ICF/MR population.)	1,409

At the present time, Kentucky has 1,203 licensed ICF/MR beds plus an additional 344 beds in a private facility which was operational many years prior to our licensure process. Based on the estimated need for ICF/MR beds, we now have sufficient institutional beds available to meet our estimated need.

Concerned Families of Hazelwood Hospital
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Louisville, Kentucky 40212
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Pat Newton, Entertainment Chairman
Elvin Myers, Historian

PRESENTATION BY:

CONCERNED FAMILIES OF HAZELWOOD HOSPITAL I.C.F MR)

TO

FINANCE SUBCOMMITTEE TO EXAMINE
MEDICAID FINANCING OF SERVICES
FOR DEVELOPMENTALLY DISABLED PERSONS

SEPTEMBER 19, 1986

SENATE DIRKSEN BLDG ROOM -215

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Concerned Families of Hazelwood is deeply concerned in any Medicaid Cuts for our mentally retarded citizens in these United States. We are also interested in why Medicaid cost has gone up millions of dollars in the last few years. We do not believe this cost is related to DIRECT CARE OF OUR M.R. CITIZENS . We believe that cost is related to LARGE SALARIES OF SO CALLED PROFESSIONALS WHICH COME IN AND DO LARGE STUDIES TO WHAT TYPE OF PROGRAMS AND TO WHERE OUR MENTALLY RETARDED CITIZENS SHOULD LIVE. .

SENATOR CHAFEE'S S.B. # 873 is an example of why cost has gone up for Medicaid. REPRESENTATIVE JOSEPH MCDADE H.R. 2523 is another example. If these elected officials had gone out and done a study of community based services verses Institutional care they would find out which is the most expensive.

Concerned Families of Hazelwood supports the concept of community alternative for those who can function in and benefit from such an environment. However , we strongly believe a spectrum of services is needed to meet the needs of all the disabled. We believe too, present needs should be met first. Senator Chafee's Bill and Representative Joseph McDade's bill strongly recommends closing of all institutions.

Senator Chafee and Representative McDade's bill is described as a bill "to amend title 19 of the Social Security Act to assist severely disabled individuals to attain or maintain their maximum potential for independence and capacity to participate in Community and family life". The bills are but another attempt to close some of our fine institutions for the mentally retarded which provide excellent care for our profoundly retarded citizens.

Some points I should like to mention:

1. 98 % or more of parents who have MR children in Kentucky Institutions (or residential facilities) want their children to remain there. Concerned parents of helpless children demand a high level of care and are pleased with the care Kentucky provides in our facilities.
2. Institutional care for medically demanding or high care MR children is far LESS costly than scattered community care offering the same servies to the same degree. There are insufficient professionals to travel about the communityand even if there eventually were, it would be extremely expensive. Terminology is important here! A parent I know says

. Page 2 continued

her daughter received physical therapy at school. She received this 2 hours a week from a PT aide. A child in Hazelwood State Facility received PT several hours daily by a licensed physical therapist with supervised PT activities intergrated into other programs througout the remainder of the day.

3. There is big $$ profit for some in providing community care. The state government in Ky. contracts out for MR community services with a Council for Retarded Citizens Agency. The agency in turn subcontracts for services with a Community Living Company who finally gets around to delivering services with whatever funds are left. (SEE ATTACHED DOCUMENTATION). Community Services Delivery is big business that lends itself to poor accountability. Correct monitoring is almost IMPOSSIBLE . Several of Kentucky's Community Comprehensive Care Agencies have taken bankruptcies due to poor management and we have reports of their delivering poor community care.

4. If an institutions is not doing it's job then look to the people who fund it and to the state officials who manage it. Kentucky and some other states have fine institutions so there is no reason for poor institutional care anywhere in the United States.

5 A recent investigation by state officials in Kentucky found that many Community foster and group homes were delivering poor care to state wards. there was even sexual abuse in these supervised community care homes. fortunately the children could talk and finally brought the matter to the attention of the officials. Think of what can happen to a totally helpless defenseless child who can neither talk, walk nor can make any of his needs known.

6. A severely disabled person is one thing but a profoundly retarded child who has no self help skills, cannot talk, who has ongoing medical problems and who functions with an IQ of 5---is quite a different kind of individual with quite different needs. Many persons with severe disabilities can care for themselves in the community with help. We are not talking of children such as these and we support community care for them. Rather, we are talking of children such as we have at Hazelwood who must have demanding around the clock care just to survive. SEE ATTACHED TO WHAT HAPPENS WHEN THIS TYPE OF CHILD LEAVES HAZELWOOD AND CANNOT SURVIVE IN THE COMMUNITY AND WHO HAD TO BE RETURNED TO HAZELWOOD TO LIVE.

Page 3 Continued

The Department of Health and Human Servies is now engaged in an evaluation of proposals to restruct Medicaid. Some parts of this study we find are very important to families who have mentally retarded children in Institutions

Family cost of sharing is an impossible task for many families if not all families who have children or family members in State and Private Institution

Medicaid cuts should be taken off of the SO CALLED PROFESSIONALS AND THEIR GREAT IDEAS OF WHAT IS RIGHT FOR ALL THE HANDICAPPED. Which we have found in Kentucky to be totally useless and none worked. We have seen them come and go in Kentucky and we have spent thousands of dollars needlessly. Don't cut (direct care services) for our chindren . Don't try to make families pay when they canot afford it. DON'T MAKE OUR MENTALLY RETARDED CHILDREN THE PAWNS .

We in the State of Kentucky are happy with our State Institutions . We are trying to get our State to hire more direct care staff and Medical. We need less Programming and more Medical. WE MUST HAVE MEDICAL FOR OUR CHILDREN TO SURVIVE AT HAZELWOOD.

I HAVE GIVEN YOU PROOF THAT INSTITUTIONS ARE CHEAPER TO RUN THAN COMMUNITY FACILITIES. WE HAVE MUCH MORE ACCOUNTABILITY IN STATE AND PRIVATE INSTITUTIONS

In summary I would like to say that handicapped, severly disabled and mentally retarded are general terms applying to many. The variety of afflictions within these groups vary. We can no more assign one type of care (Community Care) for all individuals than we can say one type of medicine should be used for all illness. Senator Chafee's Bill # 873 and the other bills does just this. It would close our Fine State & Private Institutions. I and our families who have children in these Institutions PLEAD with you DO NOT CUT MEDICAID FOR OUR CHILDREN AND PLEASE DO NOT SUPPORT SENATE BILL # 873 HOUSE BILL # 2523 and HOUSE BILL # 2902.

Louise G. Underwood, President
Concerned Families of Hazelwood
3129 Bank Street
Louisville, Kentucky 40212

Home -1 502-774-7076
Work -1 502-426-0356

COMMONWEALTH OF KENTUCKY
OFFICE FOR PUBLIC ADVOCACY
State Office Building Annex, Frankfort, Kentucky 40601

Protection and Advocacy Division
564-2967

Defense Services
Investigative Branch
564-3765

Public Defender Division
564-3734

July 25, 1983

Dr. Jeff Strully ← (this is a community comprehensive care agency)
Seven Counties Services
Box 628
Starks Building
Louisville, Kentucky 40202

Dear Dr. Strully:

I am a bit confused about the status of [redacted] application to the AIS/MR program. As I mentioned to you, I was told by Mr. Bill Draper that [redacted]'s estimated cost for community living has been placed at $40,000. I was later informed that a decision has, in fact, been made on [redacted] acceptance to this program. Please advise me if a decision has been made, if the cost estimate has been established, and if those seven residential slots are taken.

I understand that there may be some expensive initial costs in moving [redacted] into his own apartment. Early next week I will be receiving a report from Hazelwood ICF/MR as to what equipment belongs to [redacted] already and the purchase cost of any equipment [redacted] might need and does not own. I am also eager to work with Ms. Cassidy in identifying other resources in helping [redacted] establish himself in a new home in an inexpensive manner.

I would hope that before a final decision as to costs or acceptance is made from your agency that you would allow [redacted] time to obtain another cost estimate if deemed necessary, and to speak with you about the quality of the living situation [redacted] chooses to place himself in. I would assume that you would give his guardian and myself as his representative that same opportunity.

Note: At Hazelwood ICF/MR this person's care cost $23,000 per year as opposed to $40,000 per year plus initial cost of moving & setting up the apartment plus medical needs.

I am sure that we can work together to ensure that the procedures taken to determine his eligibility are working towards [redacted]'s benefit.

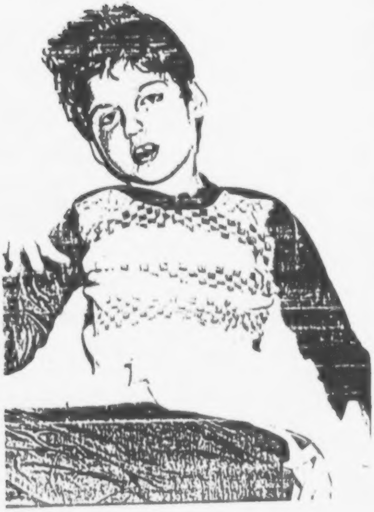
Sincerely,

Pam Clay

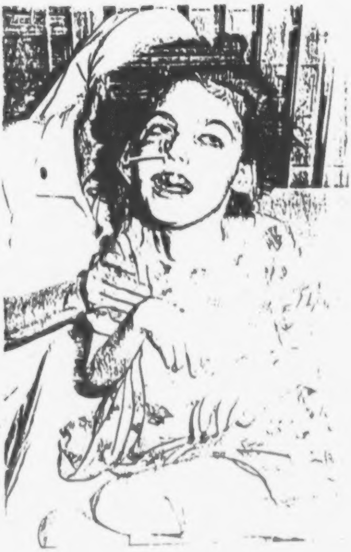
Pam Clay, Residential Advocate
Protection and Advocacy Division

PC/cyd

cc: [redacted]
Ms. Paula Corbett



BEFORE LEAVING HAZELWOOD ICF/MR
FOR COMMUNITY PLACEMENT



AFTER RETURNING TO HAZELWOOD
FROM COMMUNITY PLACEMENT

State of Wisconsin
WCDD
Council on Developmental Disabilities
One West Wilson Street/P O Box 7851 • Madison, Wisconsin 53707-7851 • (608)266-7826

August 29, 1986

TO: Members of the Senate Committee on Finance

FROM: Wisconsin Council on Developmental Disabilities
Donald D. Cannady, Chairperson

RE: Medicaid Long-Term Care Issues for the Developmentally Disabled

As a nation, we have historically undersupported family and self-care of people with disabilities in favor of more restrictive institutionalized settings. Federal, and therefore state, funding of services has been biased toward the most restrictive, least integrated settings. This skewed funding is a major disincentive to home and community life for the developmentally disabled, even though the evidence is increasingly clear that such living is more positive. Parents of a developmentally disabled child who wish to maintain their child in the home and community have had no assistance until they place their child outside their home.

In Wisconsin, three State Centers for the Developmentally Disabled serve a population of approximately 2,000 at a cost of $88 million annually. Most of the funding comes from Medical Assistance. Since 1980, Medical Assistance rate increases have been structured to penalize facilities with higher than average costs. The Centers received no rate increase in the 1985-87 budget, though costs rose to $115-$120 per day. The result was a budget deficit of $29 million for the legislature to assume. These deficits are likely to continue and to grow larger without a long-term solution.

There are many residents without medical needs inappropriately placed in the Centers because there was no community alternative available. The same is true of nursing homes, where approximately 4,000 developmentally disabled reside (60 percent under age 55).

Meanwhile basic community aids limp along without any increase in funding as waiting lists for community services grow dramatically. Community aids (state and county funds) of $75 million annually must serve 90 percent of the developmentally disabled population.

Some 2,174 persons were projected to be on waiting lists during 1985, an increase of almost 50 percent from 1984, and the dollar gap was over $9,939,524, an increase of almost 25 percent. The legislature appropriated $2 million in developmental disabilities capacity building funds for the 1985-87 biennium to help counties address the needs of unserved/underserved persons, including those on waiting lists for community services. Despite this much-needed assistance, the waiting lists for 1986 are growing at an alarming rate.

Some 59 percent of all counties currently have waiting lists, and 78 percent anticipate having waiting lists of 3,263 persons and dollar gaps of $15,628,508 before the end of 1986 unless additional resources become available. In 1986, 58 percent of all counties estimate a higher dollar gap than they had in 1985.

Federal funding that would encourage home and community living and discourage inappropriate institutional use would greatly benefit the funding distortion and imbalance in Wisconsin.

Attachment: Waiting List Data

State of Wisconsin

WCDD

Council on Developmental Disabilities

One West Wilson Street/P O Box 7851 • Madison, Wisconsin 53707 7851 • (608)266 7826

February 27, 1986

TO: All Interested Persons

FROM: Stephen Stanek, Planning Analyst

RE: WAITING LIST DATA

Each year the Wisconsin Council on Developmental Disabilities publishes data which indicate the number of people with developmental disabilities who are or will be on waiting lists to receive specific community services, and the additional dollars that are needed to serve these people. These waiting list and dollar gap data are tabulated by counties and reported to the Council on the Supplemental DD Council Data Form, which has been part of the annual county Coordinated Plan and Budget (CPB). The attached tables show data from each of the five calendar years 1982-1986, using the figures from the Supplemental DD Council Data Form for each of those years. With the recent demise of the CPB (the Legislature deleted all CPB references and requirements in the budget repair bill), it is unclear if or how any waiting list data will continue to be collected at the state level. Therefore, it is quite possible that this may be the last year in which this report is made available by the Council.

Waiting list data is a very conservative indicator of unmet needs, since it only includes people actually identified to be in need of a particular service, but who will be unserved due to fiscal or other constraints. We estimate that the total unmet needs, of people currently known or unknown to the service system, is at least ten times the numbers reflected by waiting list data.

The following tables report waiting list data for selected, basic community services. These include community living residential services (child foster and group homes, adult family homes, adult group homes, apartments and other independent living situations, respite care and family support services), daytime programs in the community (adult work-related services, adult day services, and developmental/early intervention services for children from birth to age three), case management services and Community Options Program (COP) services. These waiting lists for residential services, daytime services, case management and COP are totaled and the totals are presented in the last two columns of the table.

Most adults on waiting lists for residential services have no opportunity to choose a living environment that meets their needs and promotes their independence, and people waiting to receive daytime services typically remain at home during the day with no programs or structured activities that address their needs. This is particularly tragic for young adults who may leave the school system, find themselves on waiting lists for services, and subsequently lose many of the important skills they had acquired when they were in school. In some counties, waiting lists are so extensive and so "routine" that it is not uncommon for people to stay on waiting lists for as long as one or two or three years. Faced with these prospects, and out of profound frustration, many parents and persons with disabilities simply give up and remove themselves from waiting lists, or they never even sign up to begin with. Although these extreme phenomena exist mainly in some of the state's most populous counties, it must be noted that the very existence of waiting lists, a euphemism for denial of service, calls into serious question the state-county commitment to provide the services that all people need to live and grow in the community.

The Council believes that the attached county-generated data is reasonably accurate and credible. Most counties have established or projected waiting lists for one or more community services during this five-year period. Other counties consistently report no waiting lists, either because none exist or because the county, for various reasons, chooses not to report or acknowledge any possible waiting lists in the CPB. Some counties also vary from one year to the next in their willingness to report such data. (Please note that a designation of NA or a dash next to a county's name does not necessarily imply that there are no waiting lists or unmet needs in that county.) Nevertheless, analyses of these data over time and in conjunction with other information suggest that these are plausible indicators of minimum unmet need for the vast majority of counties and the state as a whole.

Trend data between 1982-1986 is especially noteworthy. Both the total number of people projected to be on waiting lists for basic community services and the dollars needed to serve them had been decreasing, if ever so slightly, during 1983 and 1984. This trend was suddenly reversed, however, for 1985; 2,174 persons were projected to be on waiting lists during 1985 (an increase of almost 50% from 1984), and the dollar gap was over $9,939,524 (an increase of almost 25%). Based at least in part on these data, the Legislature appropriated $2 million in DD capacity building funds for the 1985-87 biennium to help counties address the needs of unserved/underserved persons, including those on waiting lists for community services. This appropriation has enabled counties to serve many people who would not otherwise have been served. Despite this much needed assistance, however, the waiting list numbers continue to grow, and for 1986 they are growing at a very dramatic and alarming rate.

In 1985, 55% of all counties reported one or more current actual waiting lists for DD community services, and 62% projected having one or more waiting lists and a corresponding dollar gap (i.e., dollars needed to serve people on waiting lists) sometime during 1985. These numbers increase for 1986; 59% of all counties currently have waiting lists, and 78% anticipate having waiting lists and dollar gaps before the end of 1986 unless additional resources become available. In 1986, 58% of all counties estimate a higher dollar gap than they had in 1985 (24% show a smaller gap and 18% show no change). In terms of statewide totals, the number of persons on actual, current waiting lists (as of September 1, 1985) has increased almost 28% (1,501 last year, 1,914 this year), the number projected to be on waiting lists is up 50% (2,174 last year, 3,263 this year), and the amount of dollars needed is up 57% ($9,939,524 last year, $15,628,508 this year). Almost 79% of the total dollar gap exists in just six counties: Milwaukee ($5,531,740, or 35.4% of the state total), Dane ($3,572,745 or 22.9%), Outagamie ($1,077,160 or 6.9 %), Waukesha ($807,000 or 5.2%), Rock ($751,360 or 4.87%), and Winnebago ($566,500 or 3.6%).

One final note: for CY 1985 and 1986, we have included current waiting list data as well as projected numbers. For instance, 1,914 people are currently on waiting lists for services, and counties report that number will grow to 3,263 during 1986 unless additional funds become available. Each of these 1,914 people has a name, each is a citizen, each has human rights, and each has a dream to become all that they can be--if only society will provide the opportunity for the dreams to become reality. Both current and projected data are presented to reinforce to the reader that behind these statistics there are in fact real people with real needs.

We hope this data is revealing and useful. Please contact the Council if you have any questions or comments.

PERSONS WITH DEVELOPMENTAL DISABILITIES
PROJECTED TO BE ON WAITING LISTS FOR COMMUNITY SERVICES

DATA FROM 1982-1986

Compiled by Stephen Stanek
Wisconsin Council on Developmental Disabilities

February 1986

- 1986

WAITING LIST DATA FOR SELECTED BASIC COMMUNITY DEVELOPMENTAL DISABILITIES SERVICES

CY 1986

REGION; COUNTY(IES):	RESIDENTIAL: COMMUNITY LIVING AND FAMILY SUPPORT SERVICES											
	CHILD FOSTER GROUP HOMES		ADULT FAMILY HOMES		ADULT GROUP HOMES		APARTMENTS/INDEPENDENT LIVING/SRC/SLP²/		RESPITE CARE		FAMILY SUPPORT PROGRAM	
	PROJECTED/CURRENT¹/	$$ NEEDED	PROJECTED/CURRENT¹/	$$ NEEDED	PROJECTED/CURRENT¹/	$$ NEEDED	PROJECTED/CURRENT¹/	$$ NEEDED	PROJECTED/CURRENT¹/	$$ NEEDED	PROJECTED/CURRENT¹/	$$ NEEDED
SOUTHEASTERN:												
Kenosha	—	—	—	—	—	—	—	—	—	—	—	—
Ozaukee	—	—	2/1	$9,600	—	—	0/6	$25,100	—	—	—	—
Racine	—	—	—	—	—	—	—	—	—	—	—	—
Walworth	—	—	—	—	—	—	—	—	—	—	—	—
Washington	—	—	—	—	—	—	16/7	$8,300	0/5	—	—	—
Waukesha	—	—	17/7	$20,000	60/45	$540,600	12/3	$25,000	—	—	—	—
TOTAL	—	—	19/8	$29,600	60/45	$540,600	34/13	$36,600	0/5	—	—	—
MILWAUKEE:												
Milwaukee	—	—			380/144	$2,400,140	36/21	$90,300	—	—	—	—
TOTAL	—	—			380/144	$2,400,140	36/21	$90,300	—	—	—	—
EASTERN:												
Brown	2/2	$20,000	—	—	20/20	NA⁴/	10/0	NA⁴/	—	—	—	—
Calumet	—	—	—	—	3/0	$23,000	3/0	$1,300	—	—	—	—
Door	—	—	3/3	NA	—	—	—	—	—	—	—	—
Fond du Lac	NA/0	NA	6/6	$23,000	15/17	$80,000	6/3	$9,000	NA/0	NA	—	—
Green Lake	—	—	0/2	0	—	—	—	—	—	—	—	—
Kewaunee	—	—	—	—	3/0⁵/	$16,000⁵/	17/15⁵/	$13,000⁵/	—	—	—	—
Manitowoc	—	—	6/6	$24,000	—	—	—	—	15/0	$17,000	4/0	$730
Marinette	—	—	—	—	—	—	10/0	$35,000	5/0	$2,000	—	—
Marquette	—	—	—	—	—	—	—	—	—	—	—	—
Menominee	×	—	3/3	$11,500	6/6	NA	1/0	$3,000	3/3	$3,900	—	—
Oconto	—	—	—	—	—	—	2/0	$10,000	—	—	—	—
Outagamie	2/0	$3,100	20/6	$21,600	71/36	$601,600	5/0	$14,700	—	—	—	—
Shawano-Waupaca	—	—	6/0	NA	13/0	$105,000	20/0	$27,000	—	—	—	—
Sheboygan	—	—	2/0	$8,000	8/0	$64,000	3/12	$3,500	—	—	—	—
Waushara	—	—	—	—	1/0	$10,000	4/0	$4,950	—	—	—	—
Winnebago	—	—	—	—	10/0	$120,300	6/0	$80,000	10/6	$9,000	—	—
TOTAL	4+/21	$23,100+	44/36	$88,120+	148/79	$1,120,700+	88/38	$220,160+	33+/0	$32,300+	4/0	$730
NORTHERN:												
Adams	—	—	—	—	3/0	$30,000	—	—	—	—	—	
Ashland-Iron-Price	—	—	3/0	$4,000	—	—	6/0	$16,300	0/0	$4,000	10/0	$25,000
Bayfield	—	—	—	—	—	—	—	—	—	—	—	—
Douglas	—	—	—	—	—	—	—	—	—	—	—	—
Florence	—	—	—	—	—	—	—	—	—	—	—	—
Forest-Oneida-Vilas	—	—	—	—	—	—	4/3	$5,000	—	—	—	—
Langlade-Marathon	—	—	—	—	—	—	12/12	$40,000	—	—	—	—
Lincoln	—	—	—	—	—	—	—	—	—	—	—	—
Portage	—	—	—	—	—	—	5/0	$10,000	—	—	8/0	$34,000
Sawyer	—	—	—	—	—	—	—	—	—	—	—	—
Taylor	—	—	—	—	0/1	—	6/6	$3,000	—	—	—	—
Wood	—	—	2/3	NA	—	—	—	—	—	—	—	—
TOTAL	—	—	4/3	$4,000+	3/1	$30,000	31/18	$63,300	0/0	$4,000	18/0	$59,000
WESTERN:												
Barron-Burnett-Polk-Rusk-Washburn	—	—	20/20³/	NA³/	—	—	34/13³/	NA³/	—	—	—	—
Buffalo	—	—	—	—	2/0	$6,400	0/0	$10,100	—	—	NA/0	$3,000
Chippewa	—	—	—	—	—	—	—	—	—	—	—	—
Clark	—	—	—	—	—	—	—	—	—	—	—	—
Crawford	—	—	—	—	—	—	3/0	$3,000	—	—	—	—
Dunn	—	—	—	—	—	—	—	—	—	—	—	—
Eau Claire	—	—	2/0	$13,000	—	—	0/3	$13,002	5/0	$5,000	13/0	$15,000
Jackson	—	—	—	—	—	—	—	—	—	—	—	—
LaCrosse	—	—	3/3	$72,000	2/3	$60,000	14/0	$30,000	10/4	$10,000	—	—
Monroe	—	—	—	—	—	—	5/0	$11,402	—	—	—	—
Pepin	—	—	—	—	—	—	2/0	$3,000	—	—	—	—
Pierce	—	—	—	—	—	—	—	—	—	—	—	—
St. Croix	—	—	0/1	—	2/0	$10,000	0/2	$9,300	0/4	—	—	—
Trempealeau	—	—	—	—	6/6	$18,900	-	—	—	—	—	—
Vernon	—	—	—	—	3/2	$8,400	0/3	—	—	—	—	—
TOTAL	—	—	25/32	$84,000+	13/9	$91,800	60/31	$99,504+	15/8	$15,000	13+/0	$18,000
SOUTHERN:												
Columbia	—	—	10/8	$10,000	—	—	15/6	$40,000	—	—	NA/4	$12,000
Dane	—	—			166/166	$2,254,430	60/60	$236,532	—	—	60/30	$114,480
Dodge	1/0	$2,600	3/0	$7,200	0/4	$60,000	5/0	$3,000	—	—	4/1	$12,000
Grant-Iowa	—	—	—	—	—	—	—	—	—	—	—	—
Green	0/2	—	—	—	—	—	—	—	—	—	—	—
Jefferson	—	—	—	—	—	—	—	—	—	—	—	—
Juneau-Richland-Sauk	—	—	—	—	—	—	—	—	20/0	$10,500	5/2	$5,636
Lafayette	—	—	—	—	—	—	—	—	—	—	—	—
Rock	2/0	$5,000	7/0	$20,000	21/8	$221,300	51/20	$86,000	NA/0	$5,000	10/7	$20,000
TOTAL	3/2	$7,600	20+/8+	$37,200+	195/178	$2,522,810	140/95	$365,532	20+/0	$15,500	79+/52	$164,116
STATE TOTAL	7+/4	$35,300+	112+/72+	$263,720+	621/436	$4,799,320+	404/226	$938,952+	76+/33	$67,800+	114+/80	$231,866

1,334+/849+ $6,332,354+ (53.8%)

1/ Includes number of people projected to be on waiting list during 1986/number of people currently on waiting lists (as of 9/1/85).

2/ Includes residential support programs for independent and semi-independent living, i.e., supervised apartments (with either live-in or come-in staff), supportive home care, and adult daily living skill training programs.

3/ Numbers reflect underserved unmet needs (where more intensive extensive, or appropriate services are needed for persons currently served) rather than actual official waiting lists for these counties.

4/ No "$$ Needed" are specified because the county anticipates serving these individuals by funding transfers within existing resources (i.e., using Title 19 $$ through CIP and CIP II for current institution residents using CSP, increasing Title 19 collections, etc.).

5/ The unduplicated total counts for these counties are as follows: Fond du Lac 46/38, Kewaunee 30/24, Marinette 14/0, Manitowoc 25/46, Buffalo 10/0, Eau Claire 33/21, LaCrosse 40/27, and Vernon 23/14.

1986

WAITING LIST DATA FOR SELECTED BASIC COMMUNITY DEVELOPMENTAL DISABILITIES SERVICES
CY 1986

REGION: COUNTY(IES)	VOCATIONAL WORK-RELATED SERVICES		DEVELOPMENTAL				OTHER CORE SERVICES				TOTAL BASIC COMMUNITY SERVICES	
			0-3 DAY SERV./ COUNSELING/THERAPY		ADULT DAY SERVICES EDUCATION		CASE MANAGEMENT/ INTAKE ASSESSMENT		COMMUNITY OPTIONS PROGRAM (COP)			
	PROJECTED/ CURRENT a/	$$ NEEDED	PROJECTED/ CURRENT a/	$$ NEEDED	PROJECTED/ CURRENT a/	$$ NEEDED	PROJECTED/ CURRENT a/	$$ NEEDED	PROJECTED/ CURRENT a/	$$ NEEDED	PROJECTED/ CURRENT a/	$$ NEEDED
SOUTHEASTERN:												
Kenosha	--	--	--	--	--	--	--	--	--	--	--	--
Ozaukee	10/0	$23,000	--	--	--	--	--	--	--	--	20/5	$35,700
Racine	--	--	--	--	--	--	--	--	--	--	--	--
Walworth	5/0	$15,000	--	--	--	--	--	--	2/0	$9,000	7/0	$24,000
Washington	--	--	--	--	--	--	--	--	--	--	14/12	$8,900
Waukesha	18/6	$70,000	10/10	$12,000	20/0	$60,000	70/0	$90,000	10/0	$30,000	217/70	$807,000
TOTAL	33/6	$58,000	10/10	$12,000	20/0	$60,000	70/0	$90,000	12/0	$39,000	258/87	$895,309
MILWAUKEE:												
Milwaukee	90/80	$1,073,080	--	--	157/83	$1,873,324	--	--	--	--	486/338	$5,531,760
TOTAL	90/80	$1,073,080	--	--	157/83	$1,873,324	--	--	--	--	486/338	$5,531,760
EASTERN:												
Brown	60/64	$90,175	10/10	NA b/	6/6	NA b/	50/50	$10,000	10/10	$65,000+	176/130	$173,175+
Calumet	20/0	$24,050	--	--	10/0	$15,500	--	--	5/0	$5,000	37/0	$71,550
Door	--	--	--	--	--	--	--	--	--	--	3/3	NA
Fond du Lac	14/13	$41,000	NA/0	NA	5/5	$18,000	NA/0	$23,000	5/0	$38,000	51/46	$200,000
Green Lake	--	--	--	--	--	--	--	--	0/2	--	0/4	--
Kewaunee	22/10 c/	$26,000 c/	--	--	10/0 c/	$5,000 c/	30/24 c/	$16,000 c/	1/0 c/	$23,000 c/	82/63 c/	$90,000 c/
Manitowoc	15/0	NA	3/0	NA	35/0	$117,600	30/0	$13,000	12/3	$60,620	190/3	$230,770
Marinette	2/0	$6,000	--	--	--	--	--	--	--	--	17/0	$44,600
Marquette	--	--	--	--	--	--	--	--	--	--	--	--
Menominee	10/10	$5,000	23/30	$11,252	2/6	$15,060	--	--	--	--	66/71 c/	$69,320+
Oconto	--	--	--	--	--	--	--	--	2/0	$10,000	4/0	$20,000
Outagamie	30/16	$144,000	10/13	$36,000	--	--	70/30	$80,260	15/0	$85,000	237/107	$1,077,160
Shawano-Menominee	27/12	$47,000	--	--	12/0	$45,000	--	--	6/0	$35,000	90/35	$324,000+
Sheboygan	10/0	$20,000	3/0	$4,400	15/0	$17,000	--	--	--	--	41/10	$119,200
Waushara	5/0	NA	--	--	3/0	$12,037	--	--	2/0	NA	15/0	$28,507+
Winnebago	30/30	$205,000	--	--	15/5	$85,000	15/6	$25,000	NA/0	NA	114/37	$366,300
TOTAL	281/153	$617,025+	56+/60	$51,652+	108/30	$331,777+	223+/119	$167,260	56+/15	$288,220+	1,052+/569	$2,986,470+
NORTHERN:												
Adams	4/3	$22,000	--	--	--	--	--	--	--	--	7/3	$42,000
Ashland-Iron-Price	16/0	$80,430	6/0	$16,400	--	--	--	--	3/0	$9,000	51/0	$145,816
Bayfield	--	--	--	--	--	--	--	--	--	--	--	--
Douglas	--	--	--	--	--	--	--	--	--	--	--	--
Florence	--	--	--	--	--	--	--	--	--	--	--	--
Forest-Oneida-Vilas	6/0	$23,000	--	--	10/6	$40,000	--	--	--	--	20/6	$76,000
Langlade-Marathon	--	--	--	--	--	--	--	--	--	--	12/12	$40,000
Lincoln	--	--	--	--	--	--	--	--	--	--	--	--
Portage	10/4	$36,300	--	--	6/2	$32,400	10/0	NA	5/0	$32,700	36/8	$139,000+
Sawyer	--	--	--	--	--	--	--	--	--	--	8/8	$24,000
Taylor	2/2	$17,652	--	--	--	--	--	--	2/1	NA	8/8	$21,552+
Wood	--	--	--	--	--	--	--	--	--	--	2/3	NA
TOTAL	38/9	$188,600	6/0	$16,400	16/6	$80,400	10/0	NA	10/1	$41,700+	144/46	$488,000+
WESTERN:												
Barron-Burnett-Polk-Rusk-Washburn	30/20 d/	NA d/	--	--	--	--	--	--	--	--	74/59 d/	NA d/
Buffalo	10/0	$10,500	--	--	3/0	See VDS	--	--	4/0	$8,000	25/0	$46,000
Chippewa	--	--	--	--	--	--	--	--	--	--	--	--
Clark	2/0	$10,000	--	--	--	--	--	--	--	--	2/0	$10,000
Crawford	4/0	$13,930	--	--	--	--	--	--	--	--	7/0	$16,930
Dunn	--	--	--	--	--	--	--	--	--	--	--	--
Eau Claire	7/10	$27,300	--	--	--	--	--	--	3/4	$4,000	38/25	$77,302
Jackson	--	--	--	--	--	--	--	--	--	--	--	--
LaCrosse	18/19	$83,700	--	--	--	--	--	--	8/3	$107,700	55/42	$363,700
Monroe	5/0	$38,394	--	--	10/0	$3,000	--	--	--	--	20/0	$42,000
Pepin	8/0	$25,000	--	--	2/0	$8,000	--	--	--	--	12/0	$36,000
Pierce	--	--	--	--	--	--	--	--	--	--	--	--
St. Croix	10/6	$41,000	0/3	--	--	--	--	--	2/0	$2,600	30/11	$70,600
Trempealeau	2/2	$3,778	--	--	2/2	$3,778	--	--	--	--	3/8	$28,530
Vernon	10/6	$30,000	--	--	3/3	$19,500	23/23	NA	5/0	$10,000	42/35	$57,000+
TOTAL	114/63	$273,803+	0/3	--	20/5	$34,278+	23/23	NA	21/9	$133,600	[illegible]	[illegible]
SOUTHERN:												
Columbia	10/12	$30,000	--	--	6/6	$16,000	--	--	--	--	[illegible]	$100,000
Dane	150/141	$443,065	13/3	$21,296	22/13	$49,307	80/65	$76,627	40/33	$168,000	[illegible]	[illegible]
Dodge	55/47 e/	$115,000 e/	--	--	--	--	--	--	[illegible]	NA	86/43	$199,600+
Grant-Iowa	4/0	$20,000	--	--	--	--	--	--	--	--	4/0	$20,000
Green	8/7	$7,000	--	--	--	--	--	--	--	--	8/7	$7,000
Jefferson	28/32	$220,624	--	--	--	--	--	--	--	--	28/32	$220,624
Juneau-Richland-Sauk	33/5	$40,797+ e/	--	--	25/ e/	$41,756+ e/	--	--	--	--	[illegible]	$98,756+
Lafayette	--	--	--	--	--	--	--	--	--	--	--	--
Rock	20/5	$186,000	21/5	$75,000	10/6	$53,000	--	--	13/6	$90,000	[illegible]	[illegible]
TOTAL	308/2[illegible]	$1,272,486+	36/8	$96,296	63/36	$162,063+	80/65	$76,627	63/39	$258,000+	[illegible]	[illegible]
STATE TOTAL	84+/[illegible]	[illegible]	108+/81	$176,348+	384/160	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]

1,356+ 796 $6,371,777+
(39.7%)

SOURCE: CY 1986 Coordinated Plans and Budgets (CPB)/Supplemental DD Data Form

NOTE: NA=Specific numbers/data not available.

1985

WAITING LIST DATA FOR SELECTED BASIC DEVELOPMENTAL DISABILITIES SERVICES

CY 1985

REGION/ COUNTY(IES)	RESIDENTIAL: COMMUNITY LIVING — CHILD FOSTER/ GROUP HOMES — PROJECTED/ CURRENT[1]	CHILD FOSTER/ GROUP HOMES — $$ NEEDED	ADULT FAMILY HOMES — PROJECTED/ CURRENT[1]	ADULT FAMILY HOMES — $$ NEEDED	ADULT GROUP HOMES — PROJECTED/ CURRENT[1]	ADULT GROUP HOMES — $$ NEEDED	SUPERVISED APARTMENTS/ SUPP. HOME CARE/DLST[2] — PROJECTED/ CURRENT[1]	SUPERVISED APARTMENTS/ SUPP. HOME CARE/DLST[2] — $$ NEEDED	RESPITE CARE — PROJECTED/ CURRENT[1]	RESPITE CARE — $$ NEEDED
SOUTHEASTERN:										
Kenosha	--	--	--	--	--	--	--	--	5/NA	$ 3,000
Ozaukee	--	--	--	--	--	--	--	--	--	--
Racine	--	--	--	--	--	--	--	--	--	--
Walworth	--	--	--	--	--	--	--	--	--	--
Washington[3]	--	--	NA	$ 4,200	NA	$ 82,000	--	--	--	--
Waukesha	--	--	--	--	--	--	--	--	--	--
TOTAL	--	--	NA	$ 4,200	NA	$ 82,000	--	--	5/NA	$ 3,000
MILWAUKEE:										
Milwaukee	--	--	←	←	219/171	$1,752,000	33/18	$ 66,462	--	--
TOTAL	--	--	←	←	219/171	$1,752,000	33/18	$ 66,462	--	--
EASTERN:										
Brown	--	--	25/17	$227,786	30/20	$ 317,550	40/40	$ 455,320	--/4	--
Calumet	--	--	--	--	--	--	--	--	--	--
Door	--	--	3/3	NA	--	--	--	--	--	--
Fond du Lac[3]	2/2	See att	6/3	$ 22,000	13+/13	$ 42,000	--	--	--	--
Green Lake[3]	--	--	--/1	--	--	--	--	--	--	--
Kewaunee	--	--	--	--	1/1	$ 35,000	6/5	$ 3,000	--	--
Manitowoc	--	--	--	--	--	--	8/3	$ 35,000	--	--
Marinette	--	--	--	--	--	--	--	--	--	--
Marquette	--	--	--	--	--	--	--	--	--	--
Menominee	--	--	5/5	$ 19,227	4/4	$ 38,112	6/6	$ 4,000+	3/3	$ 2,000
Oconto	--	--	--	--	--	--	--	--	--	--
Outagamie	10/6	$60,000+	6/0	$120,000	14/13	$ 180,000	5/5	$ 20,000	--	--
Shawano-Waupaca	--	--	--	--	--	--	--	--	--	--
Sheboygan	--	--	3/0	$ 14,625	6/0	$ 33,670	--	--	--	--
Waushara	--	--	--	--	--	--	--	--	--	--
Winnebago	--	--	--	--	--	--	--	--	--	--
TOTAL	12/8	$60,000+	44/29	$403,638+	68+/51	$ 646,332	65/59	$ 517,320+	3/7	$ 2,000
NORTHERN:										
Adams	--	--	--	--	--	--	--	--	--	--
Ashland-Iron-Price	--	--	--	--	2/NA	$ 4,800	8/NA	$ 6,600	5/NA	$ 2,350
Bayfield	--	--	--	--	--	--	5/NA	$ 2,500	--	--
Douglas	--	--	2/2	$ 2,400	2/2	$ 9,000	2/1	$ 7,200	3/0	$ 500
Florence	--	--	--	--	--	--	--	--	--	--
Forest-Oneida-Vilas	--	--	--	--	--	--	5/0	NA	--	--
Langlade-Marathon	--	--	1/1	NA	1/1	NA	--	--	--	--
Lincoln	--	--	--	--	--	--	--	--	--	--
Portage	--	--	--	--	--	--	--	--	--	--
Sawyer	--	--	--	--	--	--	--	--	--	--
Taylor	--	--	1/1	$ 1,200	--/3	--	6/7	$ 8,400	--	--
Wood	--	--	4/8	NA	--	--	--/2	--	--	--
TOTAL	--	--	8/12	$ 3,600+	5/6	$ 13,800+	26/10	$ 24,700+	8/0	$ 2,850
WESTERN:										
Barron-Burnett-Polk-Rusk-Washburn	--	--	16/20	$ 12,000	6/6	$ 30,000	6/6	$ 120,000	--	--
Buffalo-Trempealeau	--	--	--	--	--	--	--	--	--	--
Chippewa	--	--	--	--	--	--	--	--	--	--
Clark	--	--	--	--	--	--	--	--	--	--
Crawford	--	--	--	--	--	--	--	--	--	--
Dunn	--	--	--	--	--	--	--	--	--	--
Eau Claire	--	--	--	--	--	--	--	--	--	--
Jackson	--	--	9/6	$162,000	4/1	$ 86,400	20/26	$ 22,125	35/25	$16,800
LaCrosse	--	--	--	--	--	--	4/3	$ 5,091	--	--
Monroe	--	--	--	--	--	--	6/0	$ 12,379	--	--
Pepin	--	--	--	--	--	--	--	--	--	--
Pierce	--	--	--	--	3/0	$ 5,700	16/8	$ 13,600	5/0	$ 1,000
St. Croix	--	--	--	--	--	--	1/2	$ 5,000	NA	$ 5,000
Vernon	--	--	NA/0	$ 10,000	--	--	--	--	--	--
TOTAL	--	--	25+/26	$184,000	13/7	$ 122,100	53/45	$ 178,995	40+/25	$22,800
SOUTHERN:										
Columbia	--	--	--	--	--	--	13/10	$ 30,000	--	--
Dane	--	--	←	←	175/170	$2,397,500	85/77	$ 289,000	--	--
Dodge	--	--	--	--	6/0	$ 40,900	--	--	--	--
Grant-Iowa	--	--	--	--	--	--	--	--	--	--
Green	--	--	--	--	--	--	--	--	--	--
Jefferson	--	--	--	--	--	--	--	--	--	--
Juneau-Richland-Sauk	--	--	7/3	$ 30,000	9/4	$ 16,200	--	--	--	--
Lafayette	--	--	--	--	--	--	--	--	--	--
Rock	--	--	NA/0	$ 6,132	NA/0	$ 30,000	20/6	$ 39,000	--	--
TOTAL	--	--	7+/3	$ 36,132	188+/174	$2,484,600	118/93	$ 358,000	--	--
STATE TOTAL	12/8	$60,000+	84+/70	$631,570+	493+/409	$5,100,832+	295/225	$1,145,677+	56+/32	$30,650
					940+/744	$6,968,729+				

[1] Includes number of people projected to be on waiting list during 1985/number of people currently on waiting lists (as of 9/1/84).

[2] Includes residential support programs for independent and semi-independent living, i.e., supervised apartments, supportive home care, and adult daily living skill training programs.

[3] Numbers reflect underserved unmet needs or "referral lists" rather than actual waiting lists for these counties.

1985

WAITING LIST DATA FOR SELECTED BASIC DEVELOPMENTAL DISABILITIES SERVICES
CY 1985

	VOCATIONAL		DEVELOPMENTAL				TOTAL	
REGION: COUNTY(IES)	WORK-RELATED SERVICES		0-3 DAY SERV./ COUNSELING/THERAPY		ADULT DAY SERVICES/RECR.		BASIC COMMUNITY SERVICES	
	PROJECTED/ CURRENT[1]	$$ NEEDED	PROJECTED/ CURRENT[1]	$$ NEEDED	PROJECTED/ CURRENT[1]	$$ NEEDED	PROJECTED/ CURRENT[1]	$$ NEEDED
SOUTHEASTERN:								
Kenosha	--	--	--	--	NA	NA	5+/NA	$ 3,000+
Ozaukee	--	--	--	--	--	--	--	--
Racine	--	--	--	--	--	--	--	--
Walworth	--	--	--	--	--	--	--	--
Washington[3]	NA	$ 12,618	--	--	NA	$ 7,786	NA	$ 106,806 (unduplicated pop)
Waukesha	--	--	--	--	--	--	--	--
TOTAL	NA	$ 12,618	--	--	NA	$ 7,786+	5+/0	$ 109,806+
MILWAUKEE:								
Milwaukee	244/98	$ 603,400	--	--	192/79	$210,500	688/366	$2,432,362
TOTAL	244/98	$ 603,400	--	--	192/79	$210,500	688/366	$2,432,362
EASTERN:								
Brown	20/28	$ 60,000	20/5	$ 38,583	20/10	$100,000	155/126	$1,179,439
Calumet	--	--	--	--	--	--	--	--
Door	--	--	--	--	--	--	3/3	NA
Fond du Lac[3]	15/11	$ 17,000	--	--	7/0	$ 14,000	41+/29	$ 95,000
Green Lake	--	--	--	--	--	--	--/1	--
Kewaunee[3]	8/6	$ 1,700	--	--	10/8	$ 9,000	25/20	$ 46,700
Manitowoc	12/10	NA	--	--	10/NA	NA	30/13+	$ 35,700+
Marinette	--	--	--	--	--	--	--	--
Marquette	--	--	--	--	--	--	--	--
Menominee	NA/NA	NA	64/97	$ 16,000	4/4	$ 25,000	86+/119	$ 104,339+
Oconto	--	--	--	--	--	--	--	--
Outagamie	18/15	$ 85,000	13/10	$ 25,000	3/0	$ 20,000	67/69	$ 510,000 (+$36,000 case mgmt. =$546,000)
Shawano-Waupaca	--	--	--	--	--	--		
Sheboygan	15/0	$ 34,000	--	--	10/0	$ 33,300	34/0	$ 115,595
Waushara	--	--	4/0	$ 7,455	--	--	4/0	$ 7,455
Winnebago	--	--	--	--	--	--	--	--
TOTAL	88/70	$ 177,700+	101/112	$ 87,038	64/22	$201,300+	665+/358+	$2,095,528+
NORTHERN:								
Adams	4/8	$ 14,192	--	--	--	--	4/8	$ 14,192
Ashland-Iron-Price	12/NA	$ 30,400	13/NA	$ 10,170	6/NA	$ 5,500	46/NA	$ 59,820
Bayfield	--	--	--	--	5/NA	$ 2,500	10/NA	$ 5,000
Douglas	4/0	$ 8,000	--	--	--	--	13/5	$ 27,100
Florence	--	--	--	--	--	--	--	--
Forest-Oneida-Vilas	5/0	$ 32,100	--	--	15/2	$ 83,350	25/2	$ 115,450
Langlade-Marathon	--	--	--	--	--	--	2/2	NA
Lincoln	--	--	--	--	--	--	--	--
Portage	10/6	$ 45,257	--	--	--	--	10/6	$ 45,257
Sawyer	--	--	--	--	--	--	--	--
Taylor	4/3	$ 25,152	--	--	2/2	$ 4,137	13/16	$ 38,889
Wood	6/13	$ 38,448	--	--	--	--	10/23	$ 38,448+
TOTAL	45/30	$ 193,549	13/0	$ 10,170	28/4	$ 95,487	133/62	$ 344,156+
WESTERN:								
Barron-Burnett-Polk-Rusk-Washburn	41/47	$ 60,000	7/3	$ 16,800	--	--	70/76	$ 208,800
Buffalo-Trempealeau	--	--	--	--	--	--	8/8	$ [illegible],000
Chippewa	--	--	--	--	--	--	--	--
Clark	--	--	--	--	--	--	--	--
Crawford	--	--	--	--	--	--	--	--
Dunn	--	--	--	--	--	--	--	--
Eau Claire	20/21	$ 42,000	--	--	--	--	20/21	$ 42,000
Jackson	--	--	--	--	--	--	--	--
LaCrosse	10/2	$ 70,000	--	--	5/8	$ 1,000	83/68	$ 158,323
Monroe	7/7	$ 25,560	2/0	$ 2,601	--	--	13/10	$ 34,172
Pepin	4/0	$ 32,383	--	--	4/0	$ 20,099	14/0	$ 64,581
Pierce	--	--	--	--	--	--	--	--
St. Croix	25/15	$ 73,000	12/5	$ 30,000	5/0	$ 30,000	66/28	$ 153,300
Vernon	8/5	$ 15,000	--	--	NA/0	$ 10,000	9+/7	$ 43,000
TOTAL	115/97	$ 317,943	21/8	$ 49,401	14+/8	$ 61,099	281+/216	$ 936,238
SOUTHERN:								
Columbia	5/0	$ 16,500	--	--	6/0	$ 18,000	26/10	$ 84,500
Dane	150/105	$ 450,000	21/9	$ 46,862	30/26	$ 70,000	661/387	$3,251,362
Dodge	5/0	$ 24,500	--	--	--	--	9/0	$ 65,400
Grant-Iowa	8/0	$ 40,000	7/0	$ 3,745	--	--	15/0	$ 43,745
Green	--	--	--	--	--	--	--	--
Jefferson	46/54	$ 351,624	--	--	--	--	46/54	$ 351,624+
Juneau-Richland-Sauk	--	--	10/13	$ 8,000	5/0	NA	31/20	$ 54,[illegible]+
Lafayette	--	--	--	--	--	--	--	--
Rock	11/15	$ 40,000	NA	$ 58,573	5/7	$ 15,000	36+/28	$ 186,[illegible]
TOTAL	225/174	$ 922,624	38+/22	$117,180	46/33	$103,000+	622+/499	$4,021,[illegible]+
STATE TOTAL	717+/469	$2,027,834+	173+/142	$263,789	344+/146	$679,172+	2,176+/1,301	[illegible]

1,234+/757 $2,970,795+

SOURCE: CY 1985 Coordinated Plans and Budgets (CPB) Supplemental DD Data Form

NOTE: NA=Specific numbers/data not available.

1984

WAITING LIST DATA FOR SELECTED BASIC DEVELOPMENTAL DISABILITIES SERVICES

CY 1986

REGION: (COUNTY/IES)	RESIDENTIAL: COMMUNITY LIVING									
	CHILD FOSTER/ GROUP HOMES		ADULT FAMILY HOMES		ADULT GROUP HOMES		SUPERV. APTS./ SUPP. HOME CARE		RESPITE CARE	
	# WAITING	$$ NEEDED	# WAITING	$$ NEEDED	# WAITING	$$ NEEDED	# WAITING	$$ NEEDED	# WAITING	$$ NEEDED
SOUTHEASTERN:										
Kenosha	--	--	--	--	5	$ 40,000	--	--	NA	$ 1,000
Ozaukee	--	--	1	$ 3,500	--	--	--	--	--	--
Racine	--	--	--	--	--	--	--	--	--	--
Walworth	--	--	--	--	--	--	--	--	--	--
Washington	--	--	--	--	NA	$ 80,000	--	--	NA	$ 3,375
Waukesha	--		--	--	--	--	--	--	--	--
TOTAL	--		1	$ 3,500	5+	$ 120,000	--	--	NA	$ 4,375
MILWAUKEE:										
Milwaukee	--	--	←	←	216	$1,251,562	28	$ 56,419	--	--
TOTAL	--	--	←	←	216	$1,251,562	28	$ 56,419	--	--
EASTERN:										
Brown	--	--	--	--	--	--	--	--	--	--
Calumet	--	--	--	--	--	--	--	--	--	--
Door	--	--	--	--	--	--	--	--	--	--
Fond du Lac	8	$72,000	6	$14,000	6	$ 22,500	9	$ 12,000	NA	NA
Green Lake	--	--	--	--	--	--	--	--	--	--
Kewaunee	--	--	--	--	--	--	--	--	--	--
Manitowoc	--	--	--	--	--	--	--	--	--	--
Marinette	--	--	--	--	--	--	--	--	--	--
Marquette	--	--	--	--	--	--	--	--	--	--
Menominee	--	--	7	$26,696	6	$ 196,800+	23	$ 5,800+	--	--
Oconto	--	--	--	--	--	--	--	--	--	--
Outagamie	--	--	--	--	10	$ 100,000	--	--	6	$ 2,000
Shawano-Waupaca	--	--	--	--	--	--	--	--	--	--
Sheboygan	--	--	5	$18,750	15	$ 80,719	6	$ 2,649	2	$ 803
Waushara	--	--	--	--	--	--	--	--	--	--
Winnebago	NA	NA	NA	NA	10	$ 82,000	22	$ 39,000	--	--
TOTAL	8+	$72,000+	16+	$59,446+	47	$ 482,019	60	$ 59,449	6+	$ 2,803+
NORTHERN:										
Adams	--	--	--	--	--	--	--	--	--	--
Ashland-Iron-Price	--	--	--	--	--	--	--	--	--	--
Bayfield	--	--	--	--	--	--	--	--	--	--
Douglas	--	--	1	NA	--	--	--	--	--	--
Florence	--	--	--	--	--	--	--	--	--	--
Forest-Oneida-Vilas	--	--	2	NA	1	$ 6,700	5	$ 2,000	--	--
Langlade-Marathon	--	--	--	--	--	--	--	--	--	--
Lincoln	--	--	--	--	7	$ 35,000	--	--	--	--
Portage	NA	NA	2	$16,400	NA	NA	--	--	--	--
Sawyer	--	--	--	--	2	$ 6,700	15	$ 16,000	4	$ 1,250
Taylor	--	--	12	$19,520	4	$ 48,355	13	$ 9,665	10	$ 2,100
Wood	--	--	6	NA	6	NA	--	--	--	--
TOTAL	NA	NA	23	$35,920+	20+	$ 96,755+	33	$ 27,665	14	$ 3,350
WESTERN:										
Barron-Burnett-Polk-Rusk Washburn	--	--	NA	NA	NA	NA	NA	NA	NA	NA
Buffalo-Trempealeau	--	--	--	--	3	$ 2,500	--	--	--	--
Chippewa	--	--	--	--	--	--	--	--	--	--
Clark	--	--	--	--	2	$ 25,000	5	$ 7,500	--	--
Crawford	--	--	--	--	--	--	--	--	--	--
Dunn	--	--	--	--	--	--	--	--	--	--
Eau Claire	--	--	--	--	--	--	8	$ 14,000	--	--
Jackson	--	--	--	--	--	--	--	--	--	--
LaCrosse	--	--	--	--	2	$ 20,000	--	--	6	$20,000
Monroe	--	--	--	--	--	--	10	$ 21,600	--	--
Pepin	--	--	--	--	2	$ 10,000	--	--	--	--
Pierce	--	--	--	--	--	--	--	--	--	--
St. Croix	--	--	--	--	2	NA	4	NA	6	$ 2,500
Vernon	--	--	1	$ 8,400	--	--	4	$ 5,000	4	$ 2,000
TOTAL	--	--	1+	$ 8,400+	11+	$ 57,500+	31+	$ 48,100+	16+	$24,500+
SOUTHERN:										
Columbia	--	--	--	--	3	NA	6	$ 12,000	--	--
Dane	--	--	←	←	175	$2,275,000	120	$360,000	--	--
Dodge	--	--	--	--	8	$ 86,000	24	$ 20,334	--	--
Grant-Iowa	--	--	--	--	3	$ 16,300	--	--	--	--
Green	1	$10,800	--	--	--	--	--	--	--	--
Jefferson	--	--	--	--	--	--	--	--	--	--
Juneau-Richland-Sauk	--	--	7	NA	6	NA	7	NA	--	--
Lafayette	--	--	--	--	--	--	--	--	--	--
Rock	--	--	--	--	NA	$ 19,000	--	--	NA	$ 5,500
TOTAL	1	$10,800	7	NA	195+	$2,396,300+	157	$392,334+	NA	$ 5,500
STATE TOTAL	9+	$82,800+	48+	$97,266+	494+	$4,396,136+	309+	$583,967+	36+	$40,608+

896+ $5,198,777+

SOURCE: CY 1986 COUNTY COORDINATED PLANS AND BUDGETS (CPB)/SUPPLEMENTAL DD DATA FORM

NOTE: NA=SPECIFIC NUMBERS/DATA NOT AVAILABLE

NOTE: THIS TABLE ONLY INCLUDES 51.42/.437 PROJECTED WAITING LISTS FOR SELECTED DD SERVICES. WAITING LISTS/ DOLLAR GAPS FOR, E.G., CASE MANAGEMENT ARE NOT INCLUDED.

1984

WAITING LIST DATA FOR SELECTED BASIC DEVELOPMENTAL DISABILITIES SERVICES

CY 1984

REGION: COUNTY(IES)	VOCATIONAL WORK-RELATED SERVICES # WAITING	 $$ NEEDED	DEVELOPMENTAL CHILD (0-3) DAY SERVICES # WAITING	 $$ NEEDED	 ADULT DAY SERVICES # WAITING	 $$ NEEDED	TOTAL BASIC COMMUNITY SERVICES # WAITING	 $$ NEEDED
SOUTHEASTERN:								
Kenosha	--	--	--	--	20	$ 150,000	25+	$ 191,000
Ozaukee	3	$ 26,290	--	--	--	--	6	$ 29,750
Racine	--	--	--	--	--	--	--	--
Walworth	--	--	--	--	--	--	--	--
Washington	NA	$ 32,755	NA	$ 10,776	NA	$ 28,500	NA	$ 163,636
Waukesha	--	--	--	--	--	--	--	--
TOTAL	3+	$ 59,005	NA	$ 10,776	20+	$ 178,500	27+	$ 386,136
MILWAUKEE:								
Milwaukee	92	$ 663,385	--	--	63	$ 616,500	399	$2,167,866
TOTAL	92	$ 663,385	--	--	63	$ 616,500	399	$2,167,866
EASTERN:								
Brown	--	--	--	--	--	--	--	--
Calumet	--	--	--	--	--	--	--	--
Door	--	--	--	--	--	--	--	--
Fond du Lac	15	$ 16,000	NA	NA	7	$ 21,263	69+	$ 150,263+
Green Lake	--	--	--	--	--	--	--	--
Kewaunee	--	--	--	--	--	--	--	--
Manitowoc	10	NA	--	--	5	NA	15	NA
Marinette	--	--	--	--	--	--	--	--
Marquette	--	--	--	--	--	--	--	--
Menominee	7	$ 8,736	--	--	12	$ 26,800	50	$ 262,032+
Oconto	--	--	--	--	--	--	--	--
Outagamie	26	$ 98,550	1	$ 16,000	--	--	41	$ 214,550
Shawano-Waupaca	--	--	--	--	--	--	--	--
Sheboygan	--	--	--	--	6	$ 11,099	32	$ 114,100
Waushara	--	--	--	--	--	--	--	--
Winnebago	10	$ 30,000	--	--	10	$ 20,000	52	$ 170,000
TOTAL	63	$ 153,286+	1+	$ 16,000+	38	$ 97,162+	279+	$ 930,265+
NORTHERN:								
Adams	--	--	--	--	--	--	--	--
Ashland-Iron-Price	6	$ 10,500	6	$ 6,200	6	$ 8,700	18	$ 31,400
Bayfield	--	--	--	--	--	--	--	--
Douglas	--	--	--	--	--	--	1	NA
Florence	--	--	--	--	--	--	--	--
Forest-Oneida-Vilas	4	$ 29,715	5	$ 20,504	15	$ 115,329	33	$ 174,328+
Langlade-Marathon	--	--	--	--	--	--	--	--
Lincoln	--	--	--	--	--	--	7	$ 25,000
Portage	5	$ 30,000	--	--	15	$ 75,000	22+	$ 109,600+
Sawyer	--	--	--	--	--	--	21	$ 23,950
Taylor	6	$ 64,376	--	--	2	$ 8,665	47	$ 124,611
Wood	9	$ 31,099	--	--	--	--	21	$ 31,099+
TOTAL	31	$ 143,620	11	$ 26,704	38	$ 207,694	170+	$ 519,788+
WESTERN:								
Barron-Burnett-Polk-Rusk-Washburn	NA	NA	NA	NA	NA	NA	NA	NA
Buffalo-Trempealeau	--	--	--	--	--	--	3	$ 2,500
Chippewa	--	--	--	--	--	--	--	--
Clark	10	$ 65,000	--	--	4	$ 27,000	21	$ 106,500
Crawford	--	--	--	--	--	--	--	--
Dunn	--	--	--	--	--	--	--	--
Eau Claire	8	$ 8,500	--	--	--	--	16	$ 22,500
Jackson	--	--	--	--	--	--	--	--
LaCrosse	6	$ 90,000	--	--	--	--	14	$ 90,000
Monroe	12	$ 75,000	--	--	--	--	22	$ 94,600
Pepin	2	$ 12,000	--	--	--	--	4	$ 22,000
Pierce	--	--	--	--	--	--	--	--
St. Croix	15	$ 40,000	15	$ 25,000	3	$ 10,000	45	$ 85,500+
Vernon	7	$ 20,000	--	--	--	--	16	$ 35,460
TOTAL	60+	$ 256,500+	15+	$ 25,000+	7+	$ 37,000+	161+	$ 657,000+
SOUTHERN:								
Columbia	--	--	--	--	--	--	9	$ 12,000+
Dane	65	$ 350,000	10	$ 20,000	13+	$ 135,000	363+	$3,140,000
Dodge	5	$ 23,500	--	--	NA	$ 1,691	37+	$ 131,396
Grant-Iowa	3	$ 15,000	--	--	1	$ 5,000	7	$ 36,300
Green	6	$ 13,902	--	--	NA	$ 3,200	7+	$ 27,902
Jefferson	26	$ 124,937+	--	--	--	--	26	$ 124,937+
Juneau-Richland-Sauk	7	$ 8,000	--	--	--	--	27	$ 8,000+
Lafayette	--	--	--	--	--	--	--	--
Rock	NA	$ 40,000	NA	$ 17,000	NA	$ 29,000	NA	$ 110,500
TOTAL	114+	$ 575,408+	10+	$ 37,000	14+	$ 173,891	698+	$3,591,013+
STATE TOTAL	363+	$1,851,244+	37+	$119,550+	180+	$1,310,747+	1,676+	$8,252,068+
	580+	$2,851,309+						

1983

WAITING LIST DATA FOR SELECTED BASIC DEVELOPMENTAL DISABILITIES SERVICES

CY 1983

REGION (COUNTY(IES))	RESIDENTIAL COMMUNITY LIVING									
	CHILD FOSTER HOMES		ADULT FAMILY HOMES		ADULT GROUP HOMES		SUPERVISED APARTMENTS		RESPITE CARE	
	# WAITING	$$ NEEDED	# WAITING	$$ NEEDED	# WAITING	$$ NEEDED	# WAITING	$$ NEEDED	# WAITING	$$ NEEDED
SOUTHEASTERN:										
Kenosha	--	--	--	--	--	--	--	--	NA	$ 7,000
Ozaukee	1	NA	1	$ 3,500	--	--	1+	$ 10,000	12	$ 7,500
Racine	--	--	--	--	--	--	--	--	--	--
Walworth	--	--	--	--	--	--	--	--	--	--
Washington	--	--	--	--	NA	$ 60,000	--	--	--	--
Waukesha	--	--	--	--	--	--	--	--	--	--
TOTAL	1	NA	1	$ 3,500	NA	$ 60,000	1+	$ 10,000	12+	$14,500
MILWAUKEE:										
Milwaukee	--	--	←		253	$1,274,600		→	--	--
TOTAL	--	--	←		253	$1,274,600		→	--	--
EASTERN:										
Brown	2	NA	--	--	--	--	--	--	--	--
Calumet	--	--	--	--	--	--	--	--	--	--
Door	--	--	--	--	--	--	--	--	--	--
Fond du Lac	2	$ 3,000	2	$14,400	6	$ 30,000	12	$ 8 000	NA	$ 7,500
Green Lake	1	NA	--	--	--	--	--	--	--	--
Kewaunee	--	--	--	--	--	--	--	--	--	--
Manitowoc	11	NA	--	--	5	$ 37,500	--	--	--	--
Marinette	--	--	--	--	2	$ 16,000	4	$ 25,000	10	$10,000
Marquette	--	--	--	--	--	--	--	--	--	--
Menominee	--	--	--	--	23	NA	3	NA	8	NA
Oconto	--	--	--	--	--	--	--	--	--	--
Outagamie	--	--	--	--	8	$ 73,255	7	$ 11,500	15	$ 5,250
Shawano-Waupaca	--	--	--	--	9	$ 50,000	5	$ 12,000	--	--
Sheboygan	--	--	--	--	--	--	5	NA	--	--
Waushara	--	--	--	--	--	--	10	$ 9,000	--	--
Winnebago	--	--	5	NA	--	--	--	--	--	--
TOTAL	16	$ 3,000+	7	$14,400+	53	$ 206,755+	46	$ 65,500+	33+	$17,750+
NORTHERN:										
Adams	--	--	--	--	--	--	--	--	--	--
Ashland-Iron-Price	--	--	--	--	2	$ 8,500	3	NA	--	--
Bayfield	--	--	--	--	--	--	--	--	--	--
Douglas	NA	NA	2	$ 9,600	2	$ 10,800	2	$ 9,000	--	--
Florence	--	--	--	--	--	--	--	--	--	--
Forest-Oneida-Vilas	--	--	--	--	--	--	--	--	--	--
Langlade-Marathon	--	--	--	--	--	--	--	--	--	--
Lincoln	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
Portage	--	--	2	$10,500	1	$ 8,000	--	--	--	--
Sawyer	--	--	--	--	--	--	--	--	--	--
Taylor	--	--	6	$ 3,000	4	$ 27,800	--	--	10	$ 5,000
Wood	--	--	13	NA	13	NA	--	--	--	--
TOTAL	NA	NA	23+	$23,100+	22+	$ 55,100+	5+	$ 9,000+	10+	$ 5,000+
WESTERN:										
Barron-Burnett-Polk-Rusk-Washburn	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
Buffalo-Trempealeau	--	--	--	--	--	--	--	--	--	--
Chippewa	--	--	--	--	--	--	--	--	--	--
Clark	--	--	--	--	6	$ 50,400	--	--	--	--
Crawford	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
Dunn	--	--	1	NA	2	$ 10,000	3	NA	2	$ 500
Eau Claire	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
Jackson	--	--	--	--	--	--	--	--	--	--
LaCrosse	--	--	4	$22,000	4	$ 29,000	10	$ 39,000	35	$12,000
Monroe	--	--	--	--	5	$ 45,000	NA	NA	--	--
Pepin	--	--	--	--	--	--	--	--	--	--
Pierce	--	--	--	--	--	--	--	--	--	--
St. Croix	--	--	--	--	2	NA	3	NA	--	--
Vernon	--	--	2	NA	2	NA	2	$ 1,300	1	$ 500
TOTAL	NA	NA	7+	$22,000+	21+	$ 134,400+	18+	$ 40,300+	38+	$13,000+
SOUTHERN:										
Columbia	--	--	--	--	4	NA	6	$ 12,000	--	--
Dane	--	--	←		185	$2,400,000	65	$120,000	--	--
Dodge	--	--	--	--	14	$ 150,000	2	$ 3,000	--	--
Grant-Iowa	NA	NA	NA	NA	--	--	--	--	--	--
Green	1	NA	--	--	2	$ 19,920	--	--	--	--
Jefferson	--	--	--	--	--	--	--	--	--	--
Juneau-Richland-Sauk	2	$30,000	5	$11,500	10	NA	--	--	NA	$13,700
Lafayette	--	--	--	--	--	--	--	--	--	--
Rock	3	$20,000	1	$10,000	NA	$ 6,000	--	--	--	--
TOTAL	6+	$50,000+	6+	$21,500+	215+	$2,575,920+	73	$135,000	NA	$13,700
STATE TOTAL	23+	$53,000+	44+	$84,500+	564+	$4,306,775+	143+	$259,800+	93+	$63,950+

SOURCE: CY 1983 DD (51.437) COUNTY COORDINATED PLANS AND BUDGETS (CPB)/SUPPLEMENTAL DD DATA FORM
NOTE: NA=SPECIFIC NUMBERS/DATA NOT AVAILABLE
NOTE: THIS TABLE ONLY INCLUDES 51.42/.437 PROJECTED WAITING LISTS FOR DD SERVICES.

1985

WAITING LIST DATA FOR SELECTED BASIC DEVELOPMENTAL DISABILITIES SERVICES

CY 1983

REGION: COUNTY(IES)	VOCATIONAL WORK-RELATED SERVICES		DEVELOPMENTAL CHILD (0-3) DAY SERVICES		ADULT DAY SERVICES		TOTAL BASIC COMMUNITY SERVICES	
	* WAITING	** NEEDED	* WAITING	** NEEDED	* WAITING	** NEEDED	* WAITING	** NEEDED
SOUTHEASTERN:								
Kenosha	10	$ 50,[illegible]	25	$ 45,000	20	$ 59,000	55+	$ 152,[illegible]
Ozaukee	5	$ 1[illegible]	--	--	--	--	20+	$ 35,000+
Racine	25	$ 99,380	--	--	NA	NA	25+	$ 99,380+
Walworth	--	--	--	--	--	--	--	--
Washington	--	--	--	--	--	--	NA	$ 60,000
Waukesha	NA	$ 54,376	--	--	NA	$ 40,131	NA	$ 94,507
TOTAL	40+	$ 218,734	25	$ 45,000	20+	$ 99,131+	100+	$ 465,987+
MILWAUKEE:								
Milwaukee	220	$1,098,000	--	--	--	--	473	$2,377,600
TOTAL	220	$1,098,000	--	--	--	--	473	$2,377,600
EASTERN:								
Brown	--	--	--	--	--	--	2	NA
Calumet	--	--	--	--	--	--	--	--
Door	--	--	--	--	1	$ 7,500	1	$ 7,500
Fond du Lac	5	$ 15,400	--	--	--	--	27+	$ 73,100
Green Lake	--	--	--	--	--	--	1	NA
Kewaunee	--	--	--	--	--	--	--	--
Manitowoc	10	$ 26,800	--	--	2	$ 7,000	27	$ 72,100+
Marinette	10	$ 15,000	6	$ 4,000	5	$ 7,500	37	$ 77,500
Marquette	--	--	--	--	--	--	--	--
Menominee	2	$ 11,000	NA	NA	8	$ 44,720	44+	$ 55,720+
Oconto	--	--	--	--	--	--	--	--
Outagamie	26	$ 51,000	--	--	--	--	56	$ 141,005
Shawano-Waupaca	16	$ 15,000	--	--	10	$ 15,000	40	$ 92,000
Sheboygan	--	--	NA	NA	15	NA	20	NA
Waushara	--	--	--	--	--	--	10	$ 9,000
Winnebago	11	NA	--	--	--	--	16	NA
TOTAL	80	$ 134,200+	6+	$ 4,000+	41	$ 82,520+	282+	$ 529,205+
NORTHERN:								
Adams	--	--	--	--	--	--	--	--
Ashland-Iron-Price	13	$ 25,250	6	$ 9,000	--	--	24	$ 42,750+
Bayfield	--	--	--	--	--	--	--	--
Douglas	5	$ 10,000	--	--	--	--	11+	$ 39,400+
Florence	--	--	--	--	--	--	--	--
Forest-Oneida-Vilas	8	$ 60,738	10	$ 42,815	18	$134,311	36	$ 237,864
Langlade-Marathon	NA	NA	NA	NA	NA	NA	NA	NA
Lincoln	4	$ 50,000	--	--	4	$ 50,000	8+	$ 100,000+
Portage	12	$ 58,000	--	--	29	$ 43,000	44	$ 119,500
Sawyer	--	--	--	--	--	--	--	--
Taylor	4	$ 24,000	--	--	3	$ 12,810	27	$ 72,810
Wood	16	$ 103,334	--	--	--	--	42	$ 103,334+
TOTAL	62+	$ 331,322+	16+	$ 51,815+	54+	$240,121+	192+	$ 715,260+
WESTERN:								
Barron-Burnett-Polk-Rusk-Washburn	NA	NA	NA	NA	NA	NA	NA	NA
Buffalo-Trempealeau	--	--	--	--	--	--	--	--
Chippewa	--	--	--	--	--	--	--	--
Clark	15	$ 67,500	--	--	10	$ 45,000	31	$ 162,900
Crawford	NA	NA	NA	NA	NA	NA	NA	NA
Dunn	7	$ 14,400	--	--	--	--	15	$ 24,900+
Eau Claire	NA	NA	NA	NA	NA	NA	NA	NA
Jackson	6	$ 12,500	--	--	1	$ 5,000	7	$ 17,500
LaCrosse	15	$ 51,000	--	--	5	$ 30,000	73	$ 183,000
Monroe	15	$ 15,000	--	--	--	--	70+	$ 80,000+
Pepin	--	--	--	--	--	--	--	--
Pierce	--	--	--	--	--	--	--	--
St. Croix	10	$ 34,000	5	$ 11,400	2	$ 8,200	22	$ 53,600+
Vernon	13	$ 82,000	--	--	2	$ 7,000	22	$ 90,800+
TOTAL	81+	$ 276,400+	5+	$ 11,400+	20+	$ 95,200+	190+	$ 592,700+
SOUTHERN:								
Columbia	3	$ 10,000	--	--	2	NA	15	$ 22,000+
Dane	20	$ 40,000	--	--	--	--	270	$2,560,000
Dodge	20	$ 97,500	--	--	8	$ 30,000	42	$ 270,500
Grant-Iowa	--	--	--	--	--	--	NA	NA
Green	3	$ 12,200	--	--	--	--	8	$ 32,120+
Jefferson	17	$ 91,035+	--	--	--	--	17	$ 91,035+
Juneau-Richland-Sauk	NA	NA	5	$ 3,500	NA	$ 33,000	22+	$ 91,700+
Lafayette	--	--	--	--	--	--	--	--
Rock	NA	$ 30,000	--	--	--	--	8+	$ 48,000
TOTAL	63+	$ 270,735+	5	$ 3,500	8+	$ 63,000+	376+	$3,133,355
STATE TOTAL	546+	$2,329,473+	57+	$115,515+	143+	$574,974+	1613+	$7,707,887

1982

[illegible] DATA FOR [illegible] ADULT DEVELOPMENTAL DISABILITIES SERVICES

CY 1982

REGION COUNTIES	RESIDENTIAL - COMMUNITY LIVING									
	[illegible] FOSTER HOMES		ADULT FAMILY HOMES		ADULT GROUP HOMES		SUPERVISED APARTMENTS		RESPITE CARE	
	# WAITING	$$ NEEDED	# WAITING	$$ NEEDED	# WAITING	$$ NEEDED	# WAITING	$$ NEEDED	# WAITING	$$ NEEDED
SOUTHEASTERN:										
Kenosha	--	--	10	NA	18	$ 175,000	20	NA	15	NA
Ozaukee	--	--	1	$ 3,556	--	--	--	--	10	NA
Racine	--	--	--	--	5	$ 180,000	5	NA	5	NA
Walworth	--	--	--	--	1	NA	--	--	--	--
Washington	--	--	--	--	1	$ 29,094	--	--	--	--
Waukesha	--	--	5	NA	15	$ 70,000	7	NA	--	--
TOTAL	--	--	16	$ 3,556+	40	$ 454,094+	32	NA	30	NA
MILWAUKEE:										
Milwaukee	NA	NA	←	←	104	$ 900,000+	→	→	NA	NA
TOTAL	NA	NA	←	←	104	$ 900,000+	→	→	NA	NA
EASTERN:										
Brown	NA	NA	NA	NA	NA	NA	NA	NA	--	--
Calumet	--	--	--	--	--	--	--	--	--	--
Door	--	--	5	NA	--	--	NA	$ 5,318	→	→
Fond du Lac	1	NA	2	NA	1	$ 7,800	20	$22,200	40	$20,000
Green Lake	←	←	←	←	NA	$ 7,981	→	→	→	→
Kewaunee	2	NA	--	--	2	$ 22,933	3	NA	2	NA
Manitowoc	NA	NA	NA	NA	--	--	2	$14,941	--	--
Marinette	←	←	1	$ 80,000	→	→	→	→	--	--
Marquette	←	←	←	←	4	NA	→	→	→	→
Menominee	13	NA	4	NA	7	$ 96,168	6	NA	15	NA
Oconto	←	←	←	←	NA	$ 58,624	→	→	→	→
Outagamie	4	NA	--	--	10	$ 100,000	8	NA	15	NA
Shawano-Waupaca	--	--	20	NA	11	$ 30,000	8	NA	--	--
Sheboygan	--	--	2	NA	10	$ 63,000	5	NA	--	--
Waushara	←	←	←	←	NA	$ 5,000	→	→	→	→
Winnebago	6	NA	--	--	4	$ 102,214	8	NA	--	--
TOTAL	26+	NA	34+	$ 80,000+	49+	$ 493,720+	60+	$42,459+	72	$20,000+
NORTHERN:										
Adams	←	←	←	←	NA	$ 12,000	→	→	→	→
Ashland-Iron-Price	2	NA	←	←	←	←	←	←	4	$51,670
Bayfield	1	NA	4	NA	3	$ 40,031	4	NA	3	NA
Douglas	--	--	2	NA	10	$ 50,000	2	NA	2	$ 5,000
Florence	--	--	--	--	--	--	NA	$ 3,600	→	→
Forest-Oneida-Vilas	--	--	3	$ 7,985	--	--	--	--	3	NA
Langlade-Marathon	2	NA	2	NA	15	$ 227,004	15	NA	200	NA
Lincoln	--	--	2	NA	3	NA	3	NA	3	NA
Portage	2	NA	2	NA	1	$ 5,000	--	--	--	--
Sawyer	←	←	←	←	NA	$ 3,456	→	→	→	→
Taylor	3	NA	6	NA	4	$ 120,000	10	NA	10	NA
Wood	--	--	--	--	3	$ 26,311	--	--	--	--
TOTAL	10+	NA	21+	$ 7,985+	39+	$ 483,802+	34+	$ 3,600+	225+	$56,670+
WESTERN:										
Barron-Burnett-Polk-Rusk-Washburn	--	--	←	←	10	$ 80,000	--	--	10	NA
Buffalo-Trempealeau	--	--	--	--	--	--	--	--	--	--
Chippewa	--	--	--	--	NA	$ 46,500	→	→	--	--
Clark	--	--	--	--	NA	$ 19,200	--	--	--	--
Crawford	--	--	--	--	1	$ 7,474	1	$13,193	NA	$ 3,000
Dunn	--	--	--	--	3	NA	--	--	--	--
Eau Claire	--	--	--	--	--	--	10	$19,252	5	NA
Jackson	←	←	←	←	NA	$ 20,000	→	→	→	→
LaCrosse	--	--	--	--	10	$ 110,000	6	NA	6	NA
Monroe	--	--	--	--	--	--	4	$ 7,400	--	--
Pepin	1	NA	2	NA	3	$ 20,000	2	NA	5	NA
Pierce	←	←	←	←	NA	$ 8,000	→	→	→	→
St. Croix	--	--	--	--	2	$ 17,208	--	--	--	--
Vernon	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
TOTAL	1+	NA	2+	NA	29+	$ 328,382+	23+	$39,845+	26+	$ 3,000+
SOUTHERN:										
Columbia	--	--	--	--	3	$ 20,000	--	--	--	--
Dane	10	NA	10	NA	204	$1,000,000	40	NA	--	--
Dodge	5	NA	5	NA	22	$ 294,024	5	NA	NA	NA
Grant-Iowa	←	←	←	←	NA	$ 46,106	→	→	→	→
Green	←	←	←	←	NA	$ 14,400	→	→	→	→
Jefferson	--	--	--	--	--	--	--	--	--	--
Juneau-Richland-Sauk	--	--	8	NA	10	NA	--	--	--	--
Lafayette	1	NA	1	$ 19,624	--	--	--	--	--	--
Rock	3	NA	3	$ 65,040	--	--	--	--	--	--
TOTAL	19	NA	27	$ 84,664+	239+	$1,364,530+	45	NA	NA	NA
STATE TOTAL	56+	NA	100+	$176,205+	500+	$4,024,528+	194+	$85,904+	353+	$79,670+

1982

WAITING LIST DATA FOR SELECTED BASIC DEVELOPMENTAL DISABILITIES SERVICES

CY 1982

REGIONS: COUNTY(IES)	VOCATIONAL		DEVELOPMENTAL				[illegible]	
	WORK-RELATED SERVICES		CHILD (0-3) DAY SERVICES		ADULT DAY SERVICES		BASIC COMMUNITY SERVICES	
	# WAITING	$$ NEEDED	# WAITING	$$ NEEDED	# WAITING	$$ NEEDED	# WAITING	$$ NEEDED
SOUTHEASTERN:								
Kenosha	50	$ 150,000	10	NA	125	$ 450,000	249	$ 225,000+
Ozaukee	10	$ 32,700	4	$ 9,318	--	--	25	$ 45,634+
Racine	19	$ 70,000	--	--	4	$ 5,000	38	$ 255,000+
Walworth	--	--	--	--	--	--	1	NA
Washington	10	$ 26,390	--	--	5	$ 17,888	16	$ 73,172
Waukesha	20	$ 65,000	10	NA	9	$ 48,000	66	$ 193,000+
TOTAL	109	$ 344,150	24	$ 9,318+	143	$ 520,888	394	$1,232,206+
MILWAUKEE:								
Milwaukee	293	$1,000,000	→	→	→	→	397+	$1,900,000+
TOTAL	293	$1,000,000	→	→	→	→	397+	$1,900,000+
EASTERN:								
Brown	--	--	--	--	--	--	NA	NA
Calumet	--	--	--	--	--	--	--	--
Door	NA	$ 14,420	←	←	NA	$ 22,993	5+	$ 42,631+
Fond du Lac	15	$ 38,291	15	$ 28,942	10	$ 28,942	104	$ 146,175+
Green Lake	NA	$ 31,251	←	←	NA	$ 89,519	NA	$ 128,750
Kewaunee	5	$ 24,990	3	NA	5	$ 24,990	22	$ 72,913+
Manitowoc	10	$ 28,999	5	$ 1,439	5	$ 6,316	22+	$ 69,695+
Marinette	8	$ 66,000	5	$ 15,000	5	$ 42,000	19	$ 203,000
Marquette	NA	NA	NA	NA	NA	NA	4+	NA
Menominee	26	$ 140,702	8	$ 8,000	10	$ 22,212	89	$ 267,082+
Oconto	NA	$ 94,387	←	←	NA	$ 95,516	NA	$ 249,527
Outagamie	30	$ 81,810	10	$ 10,000	--	--	77	$ 191,810+
Shawano-Waupaca	15	$ 60,000	--	--	10	$ 40,000	64	$ 130,000+
Sheboygan	10	$ 20,000	15	$ 15,000	25	$ 63,000	67	$ 161,000+
Waushara	--	--	--	--	2	$ 8,500	2+	$ 13,500
Winnebago	15	$ 37,515	--	--	15	$ 18,750	48	$ 156,479+
TOTAL	134+	$ 638,365+	61+	$ 78,381+	87+	$ 458,637	523+	$1,811,562+
NORTHERN:								
Adams	--	--	--	--	--	--	NA	$ 12,000
Ashland-Iron-Price	9	$ 38,899	5	$ 10,000	5	$ 37,600	25	$ 139,169+
Bayfield	2	$ 35,553	4	$ 4,000	5	$ 14,515	26	$ 94,099+
Douglas	10	$ 30,000	--	--	--	--	26	$ [illegible],000+
Florence	NA	$ 4,000	--	--	NA	$ 4,000	NA	$ 11,600
Forest-Oneida-Vilas	35	$ 178,962	--	--	1	$ 3,765	42	$ 190,212
Langlade-Marathon	8	$ 42,992	←	←	NA	$ [illegible],475	242+	$ 430,421+
Lincoln	2	NA	--	--	2	NA	15	NA
Portage	10	$ 15,000	3	$ 3,000	4	$ 12,000	22	$ 35,000+
Sawyer	--	--	←	←	NA	$ 7,258	NA	$ 10,714
Taylor	15	$ 52,000	4	$ 8,000	10	$ 40,000	62	$ 220,000+
Wood	10	$ 36,562	--	--	--	--	33	$ 62,873
TOTAL	101+	$ 433,968+	16+	$ 25,000+	27+	$ 279,063+	473+	$1,290,088+
WESTERN:								
Barron-Burnett-Polk-Rusk-Washburn	50	$ 100,000	--	--	NA	$ 50,000	70+	$ 230,000+
Buffalo-Trempealeau	NA	$ 9,928	--	--	NA	$ 12,777	NA	$ 22,705
Chippewa	NA	$ 10,000	NA	$ 3,000	NA	$ 15,750	NA	$ 75,250
Clark	NA	$ 15,384	←	←	NA	$ 18,798	NA	$ 53,392
Crawford	2	$ 14,269	--	--	NA	$ 8,768	8+	$ 46,704
Dunn	3	NA	--	--	--	--	6	NA
Eau Claire	8	$ 15,644	←	←	NA	$ 20,000	23+	$ 54,996+
Jackson	6	$ 50,000	--	--	1	$ 30,000	7+	$ 100,000
LaCrosse	24	$ 90,500	--	--	5	$ 75,000	51	$ 275,500+
Monroe	5	$ 8,200	--	--	4	$ 7,700	13	$ 23,300
Pepin	5	$ 25,000	2	$ 2,000	5	$ 23,090	25	$ 70,000+
Pierce	NA	$ 8,000	--	--	--	--	NA	$ 16,000
St. Croix	4	$ 13,700	--	--	2	$ 14,072	8	$ 44,980
Vernon	NA	NA	NA	NA	NA	NA	NA	NA
TOTAL	107+	$ 360,625+	2+	$ 5,000+	17+	$ 275,865+	207+	$1,012,717+
SOUTHERN:								
Columbia	5	$ 37,500	--	--	--	--	8	$ 57,500
Dane	20	$ 40,000	--	--	10	$ 20,000	294	$1,060,000+
Dodge	15	$ 45,301	--	--	10	$ 53,668	62+	$ 193,033+
Grant-Iowa	NA	$ 45,353	←	←	NA	$ 115,481	NA	$ 206,940
Green	6	$ 24,838	--	--	1	$ 3,812	7+	$ 33,050
Jefferson	10	$ 25,000	NA	$ 45,000	NA	$ 105,000	10+	$ 175,000
Juneau-Richland-Sauk	--	--	4	NA	--	--	22	NA
Lafayette	4	$ 6,337	--	--	--	--	6	$ 25,961+
Rock	10	$ 44,440	5	$ 34,859	5	$ 100,000	26	$ 244,339+
TOTAL	70+	$ 268,809	9+	$ 79,859+	26+	$ 397,961	435+	$2,195,923+
STATE TOTAL	814+	$3,045,917+	112+	$197,558+	300+	$1,932,414+	2,429+	$9,542,196+

TESTIMONY

JUDY CRAIG
(817) 478-6556
ROUTE THREE BOX 490-B
FORT WORTH, TX 76140

To: U.S. SENATE FINANCE SUBCOMMITTEE ON HEALTH, SENATOR DAVE DURENBERGER, CHAIRMAN

Subject: MEDICAID FUNDING OF SERVICES FOR DEVELOPMENTALLY DISABLED PERSONS

Date of Hearing: September 19, 1986
Date Written Testimony Submitted: October 1, 1986

My name is Judy Craig. I am the mother of a profoundly retarded son, who is a resident of Fort Worth State School, Fort Worth, Texas. My son's mental age is nine months, although in calendar years he is 28. I cared for him at home for 21 years and have been active as a Volunteer at the state school since we placed him there seven years ago. I am a member of Congress of Advocates for the Retarded, a member of Parent Association for the Retarded of Texas and currently serve as secretary, and I am the president of Fort Worth State School Parents' Association. As spokesperson for the parents and guardians of clients at Fort Worth State School, I am requesting that this written testimony be made a part of the above referenced hearing.

In the latter part of 1985 Fort Worth State School Parents' Association conducted a survey of parents and guardians of residents of Fort Worth State School regarding their wishes for appropriate residential placement of their children/family members. Of the more than 200 questionnaires returned, an overwhelming majority of 95 percent preferred their child/family member remain at Fort Worth State School. The reasons for their choice of state school placement over community alternatives included a need for the least restrictive setting and safety, that is the parents/guardians were in favor of a setting that allowed their children of family members to move freely about the campus and still have a protective environment.

Fort Worth State School has a spacious campus of approximately 270 acres which was donated by a local foundation. There are five residential units. Each unit has about 80 clients living in and receiving specialized training and supervision in it. The campus has all the components necessary for daily living. Other buildings house an infirmary, food service, laundry, supply, clothing inventory, maintenance, motor pool, recreation, hydrotherapy, occupational and physical therapy, and administrative services. Professional staff include physicians, psychologists dentists, dieticians, nurses, teachers, physical therapists, occupational therapists, audiologist, speech therapists and managers. Residents are taken on off-campus excursions for recreational and cultural events in addition to the numerous activities on campus.

In response to the survey parents/guardians had praise for the opportunity of contact with various persons afforded at the school - staff, visitors, other building employees, volunteers, and other clients. Some parents/guardians stated that their children/family members enjoyed a friendship of many years with other clients. The parents/guardians commented on the easy accessibility of recreational, religious, medical and dental facilities. The 24-hour supervision with nurses in attendance and back-up staff was another reason parents/guardians chose the state school setting. Additionally, the parents/guardians found Fort Worth State School convenient to visit as it is located within a large metropolitan area. Furthermore, government funding and governmental controls stabilize a much needed facility.

Parents/guardians listed a multitude of medical and behavioral problems as further reasons for choosing state school placement. For example: 76 percent of Fort Worth State School clients fall within a range of severe to profound retardation, 50 percent have convulsive disorders, 48 percent are mobility impaired, and many clients suffer from severe medical and behavioral disabilities requiring a physician's and/or physchologist's care on a regular basis. The clients generally lace self-help skills and are not able to articulate their most basic needs. There are clients at the school whose behavior would result in harm to other persons as well as to themselves if they were not in a structured setting with close monitoring by trained professional staff. The majority of the clients have little or no concept of danger or self-preservation skills. They have a low tolerance to change. Many have lived in a state school setting for most of their lives. Parents/guardians placed their children/family members in Fort Worth State School because it is the very best place for them. Parents/guardians state that if their children/family members were moved to a community setting, they would be subjected to prejudice, neglect and abuse. Since few can communicate effectively, the abuse, neglect and prejudice would go on for years without anyone knowing. Group homes or foster care do not have the checks and balances that are a part of an institution. Care givers will be their own monitors and will not report their abuse or neglect of vulnerable persons placed in their care. Neighbors and the public will not accept these profoundly retarded persons. The burn-out rate of care givers will threaten the security of the mentally retarded.

Parents/guardians whose children/family members had been in community settings (group homes) in the past also responded to the survey. Those parents/guardians were very critical of the care their children/family members received in group homes, and they now prefer state school placement.

In addition to compiling the results of the survey, I also talk to other parents/guardians of residents in state schools in Texas as well as to the public in general. Everyone I talk to is very concerned about the current national trend toward de-institutionalization of services for mentally retarded persons. These institutions are mini communities that serve the needs of persons who cannot function independently in society. Far sighted legislators have appropriated funds for construction of these institutions and for their improvement and maintenance. The institutions are the only proven cost-effecient providers of care for the mentally retarded. Almost half a century and countless dollars have been spent on improving the residential, vocational, phychological and esthetic qualities of institutions designated as residential facilities for mentally retarded Americans.

A segment of the population believes the civil rights of severely and profoundly retarded persons will be violated if they do not live outside of the institutions which are mini communities that serve their every need. These self styled experts would have you believe that the private sector will take over the responsibility of providing care for the mentally retarded with no thought of financial gain for themselves. Nothing could be farther from the truth. No one goes into business unless they intend to make a profit. When they cannot make a profit they file for bankruptcy. Our children/family members will be sent home (if available) and others will be shuffled around like pawns on a chessboard. There is no guarantee the private providers will be in business for as long as our children/family members will need residential services and intensified personal care. Bills like S.873 and S.1948 would virtually destroy a system badly needed by persons who are too handicapped to speak for themselves.

As parents/guardians we are the natural advocates for our children and family members' rights. We have a stronger committment to our children/family members than any professional, any philanthropist, or any public servant. We have and will continue to give of our resources to state schools where our children/family members live. We deserve to be heard, and our words deserve the utmost consideration. We should have the right to a choice of residential settings for our children/family members who are developmentally disabled.

We will have this choice if legislators continue to have the foresight to appropriate funds, such as the Title XVIII and XIX Social Security Funds (Medicaid) for a balanced system of services for the mentally retarded--including state schools for the mentally retarded.

Note: A sampling of the survey questionnaire is attached with other information.

JUDY CRAIG
(817) 478-6556
ROUTE THREE BOX 490-B
FORT WORTH, TX 76140

This is a copy of the survey sent to parents at Fort Worth State School to determine their preference of placement---community or state school. Responses have been typed verbatim to provide anonymity.

FORT WORTH STATE SCHOOL PARENTS' ASSOCIATION

PARENT/GUARDIAN RESIDENTIAL PLACEMENT SURVEY

August, 1985

1. Do you feel that the present placement of your family member is the most appropriate? Yes__x__ No_____
2. Do you want your family member to continue to live on the Fort Worth State School Campus? Yes__x__ No_____
3. Do you want your family member to be moved from the Fort Worth State School Campus to an alternative living facility? Yes_____ No__x__
4. If your answer to #3 is yes, which of the following do you prefer?
   - a. Your Home_____
   - b. Group Home - ICF-MR Facility* _____
   - c. Group Home - Non-ICF-MR Facility_____
   - d. Nursing Home _____
   - e. Personal Care Home_____
   - f. Other _____
5. Why do you feel that your choice of placement is the most appropriate for your family member? Yes

______ is near her grandmother & sisters in Dallas who care for visiting them & buying cloths, dentists, eye care

COMMENTS: (Write on back, or use additional paper, if needed)

We feel that _____ present placement at the Fort Worth State School is most appropriate mainly because of her physical handicaps _____ must walk with crutches and sometimes has the aid of a wheel chair for long distances. She has been placed in dorms which provide her with the most aid as she has poor personal Hygiene skills. She has always needed help with her baths and help with shampooing her hair.

Return form by Sept. 5, 1985 to:

Nancy Ward
4636 Harley Avenue
Fort Worth, TX 76107

*ICF-MR - Intermediate Care Facility for the Mentally Retarded

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FORT WORTH STATE SCHOOL PARENTS' ASSOCIATION

PARENT/GUARDIAN RESIDENTIAL PLACEMENT SURVEY

August, 1985

1. Do you feel that the present placement of your family member is the most appropriate? Yes_X_ No_____
2. Do you want your family member to continue to live on the Fort Worth State School Campus? Yes_X_ No_____
3. Do you want your family member to be moved from the Fort Worth State School Campus to an alternative living facility? Yes_____ No_X_
4. If your answer to #3 is yes, which of the following do you prefer?
    - a. Your Home_____
    - b. Group Home - ICF-MR Facility* _____
    - c. Group Home - Non-ICF-MR Facility_____
    - d. Nursing Home _____
    - e. Personal Care Home_____
    - f. Other _____
5. Why do you feel that your choice of placement is the most appropriate for your family member? _____ was previously in a small grope home It was a bad experience for her. I feel a small group home is not in her best interest.

COMMENTS: (Write on back, or use additional paper, if needed)

1. _____ can not be confined to a small area. She is very nervous and hyperactive.Confinment to a small area, such as a group home only aggervates her condition. Additional medication to sedate her is totally out of the question.

2. The employees at the group home were most unsatisfactory. They were not qualified for their possitions. The weekend help was who and what ever they could drag up. As long as it was a worm body it seemed to satisfy the state.

Return form by Sept. 5, 1985 to:

Nancy Ward
4636 Harley Avenue
Fort Worth, TX 76107

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FORT WORTH STATE SCHOOL PARENTS' ASSOCIATION

PARENT/GUARDIAN RESIDENTIAL PLACEMENT SURVEY

August, 1985

1. Do you feel that the present placement of your family member is the most appropriate? Yes_X__No_____
2. Do you want your family member to continue to live on the Fort Worth State School Campus? Yes_X__No_____
3. Do you want your family member to be moved from the Fort Worth State School Campus to an alternative living facility? Yes_____No_X___
4. If your answer to #3 is yes, which of the following do you prefer?
   - a. Your Home_____
   - b. Group Home - ICF-MR Facility* _____
   - c. Group Home - Non-ICF-MR Facility_____
   - d. Nursing Home _____
   - e. Personal Care Home_____
   - f. Other _____
5. Why do you feel that your choice of placement is the most appropriate for your family member? Because she cannot bathe properly, or wash her teeth without prompting and help. She has no knowledge of cooking or washing dishes, she cannot wash her own hair - too many

COMMENTS: (Write on back, or use additional paper, if needed)

things would have to be done for her it would not be practical. We are older parents with sickness in the family, Mother works - Cannot handle any additional problems and frustrations over this child at this time in life!

Return form by Sept. 5, 1985 to:

Nancy Ward
4636 Harley Avenue
Fort Worth, TX 76107

*ICF-MR - Intermediate Care Facility for the Mentally Retarded

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FORT WORTH STATE SCHOOL PARENTS' ASSOCIATION

PARENT/GUARDIAN RESIDENTIAL PLACEMENT SURVEY

August, 1985

1. Do you feel that the present placement of your family member is the most appropriate? Yes X No _____
2. Do you want your family member to continue to live on the Fort Worth State School Campus? Yes X No _____
3. Do you want your family member to be moved from the Fort Worth State School Campus to an alternative living facility? Yes _____ No X
4. If your answer to #3 is yes, which of the following do you prefer?
   - a. Your Home _____
   - b. Group Home - ICF-MR Facility* _____
   - c. Group Home - Non-ICF-MR Facility _____
   - d. Nursing Home _____
   - e. Personal Care Home _____
   - f. Other _____
5. Why do you feel that your choice of placement is the most appropriate for your family member? FWSS provides facilities to meet all a clients needs. The freedom to move about the campus gives a feeling of independence.

COMMENTS: (Write on back, or use additional paper, if needed) "Least restrictive living" should be defined: a living facility which provides the most freedom to move around and have access to activities without being bussed everywhere. FWSS has a program to develop the total individual.

Return form by Sept. 5, 1985 to:

Nancy Ward
4636 Harley Avenue
Fort Worth, TX 76107

*ICF-MR - Intermediate Care Facility for the Mentally Retarded

PO BOx 427
Meridian, Ms. 39302
September 30, 1986

Ms. Betty Scott-Boom
Committee on Finance, Room SD-219
Dirksen Senate Office Bldg.
Washington, D. C. 20510

Re: Sen. Packwood's Hearing to Examine
Medicaid Financing of Services for
Developmentally Disabled Persons

Gentlemen:

As representatives of the families of residents in the various retardation centers in Mississippi, we would like to express our opinion concerning the Medicaid funding. We fell that we get the best service for each dollar spent than probably any other state. The administrators and staff of our centers run each one with extreme efficiency but still provide the necessary services to give the residents a high standard of living.

While we realize that group home or alternate living arrangements have their place for mildly retarded, we feel it is essential to maintain a large facility that can provide all services for the more severely or profoundly disabled. Medicaid funding is absolutely necessary for this type facility and we urge you to continue to fund institutions sufficiently to take care of our mentally retarded citizens. You are invitedto inspect our facilities in Mississippi at any time to see how these funds are being spent.
Thank you.

Very truly yours,

Mr + Mrs Jim Crawford

Mr. and Mrs. Jim Crawford
Co-President
State Association of Parents, Guardians
and Friends of the Mentally Retarded

Maurice Dayan, Ed.D.
P. O. Box 5191
Pineville, LA 71361-5191

September 15, 1986

Ms. Betty Scott-Boom
Committee on Finance
Room SD-219
Dirksen Senate Office Building
Washington, D.C. 20510

Dear Ms. Scott-Boom:

Re: Medicaid Financing of Services for Developmentally Disabled Persons

I would appreciate if this letter is included in the printed record of the hearing scheduled September 19, 1986.

As a professional who has served developmentally disabled persons in all the continum settings, large residential, small residential, community homes, foster care in their own homes, etc. and a professional who has provided services in public schools, community settings, residential facilities, supportive work and sheltered workshop, and as a volunteer citizen who has served as President of local Assocations for Retarded Citizens, and has served on Boards of Organizations concerned with the developmentally disabled as well as on numerous advisory boards including several Governor's Advisory Boards, I feel I can present a balanced testimony related to the current funding provided through the Medicaid Programs, the range of services delivered and type of setting most appropriate for the long-term care of developmentally disabled persons.

1. Explanation of the Increase Medicaid Funds from $655 Million in 1976 to $4.7 Billion in 1985

    a. Inflation rate - There is no reason not to believe that a minor cause of increases costs to Medicaid was inflation.

    b. Costs to Meet ICF/MR Standards - Prior to 1976 there was literally no residential facility large or small, including clients in their own home that were meeting the present professional standards of service for developmentally disabled. In fact, if one compares copies of the written standards as they evolved one can see as funds were made available the standards became more demanding thus more costly. Although the intent of the original Title XIX Amendments to the Social Security Act was to improve the quality of care for the small 3-4% of the mentally retarded being inadequately served in the large residential facilities, the quality of care did improve, but the excessive monitoring, documentation and unrealistic standards brought about a poor-cost effective way of improving quality care.

> The cost of increase direct-care staffing, unwritten therefore unlimited suggested professional - client staff ratios, and inferred and interpreted requirements of involvement of every imaginable professional whether needed or not contributed to the increase cost of Medicaid. The funding system rewarded states to triple their Medicaid costs.

A state with a 75-25 Federal match could triple their costs of services without expenditure of any additional state dollars, then they could innovatively identify new or additional state dollars to match by using third party administration of funds. By innovatively depreciating buildings and equipment purchased over a twenty or thirty year time period, they increased the Medicaid match with no substantial increase in new state dollars.

Furthermore, since this was reimbursed money there was and is no requirement for the states to use the reimbursed funds for qualified developmentally disabled clients.

1. Implied Affect of Litigation - As states were bombarded with litigation they added "program costs" not always directly attributable to Title XIX Standards to their overall reimburseable Title XIX programs. It was easier to implement a program because the "Feds" were going to pay for it anyhow then to fight the litigation and to determine if the program was really needed or indicated.

2. Misinterpretation of the State of the Art - Although Behavior Modification Technology was on its way as early as 1963 and 1964, and by 1976 had brought about a major improvement in the care and training of mentally retarded clients, with funds available from Medicaid we hired new professionals who spent excessive amounts of time writing and developing Behavior Management Technology and in many cases, years later not even implementing the written programs because new terminologies and procedures suggested that the programs had to be rewritten. Behavior Management Technology developed false hopes among parents, teachers, trainers, and Psychologists by misinterpretations of the concept of the developmental model, normalization and least restrictive alternative - and Title XIX paid for new professional to try their hand at Behavior Modification Technology. More personnel was hired to spend time on program writing or documentation which resulted in less actual time providing direct service to clients.

3. Fire and Safety Codes and Accessibility - In the 1950's and 1960's there is no doubt that many of the facilities were inadequate and placed many of the clients in residential settings, large facilities, small facilities, their own homes at risk, but because Medicaid funds were available to meet standards, we see that the codes and the monitors of the codes become excessively strict and again states and administrators made the suggested changes even though in their own professional minds it was not required.

   c. The Smaller the Better Lie - As states and administrators brought into the concept that smaller is better, then it was natural that the per diem costs would rise. We see a differential between $50 per day to $150 per day between the largest and smallest ICF-MR's. From 1976 to date the states increased the number of residential facilities but reduced the size of the facilities to meet the "closer to home" and more "normalizing" concepts. Somewhere along the evolution process legislators, senate finance committees, and state planners appeared to believe the lie that you could serve clients in homelike settings and home-size settings cheaper than in large residential facilities. Where clients were centralized to provide quality care they were decentralized and dispersed across the states with some magical hope that qualified professionals would be available whereever the clients resided and somehow it would be cheaper.

d. The Generic Service Lie - As facilities began to serve fewer clients and dispersed across the state then came the philosophical arguments that most of the services could be provided by the community generic service system. So at a time when the entire nation was facing "using health costs" the MR system began to tie into these community generic health systems and of cause it wasn't cheaper than your full-time and employed professionals in the large residential facilities.

e. Inclusion of New Clients - Besides the costs of meeting Title XIX standards the second major explanation for the increase of Medicaid funds is the inclusion of clients not previously served.

1. New Definition - Although the original legislation was designed to meet the needs of the 3-4% of the mentally retarded who were in residential facilities, Title XIX defined eligibility to mentally retarded and other developmentally disabled. The Developmentally Disabled Council and redefinition of Developmental Disabilities opened the door for large numbers of underserved or unserved clients including autistic, deaf-blind, and profound physically handicapped. Some states even redefined many of their mentally-ill clients to tie into this "Money Bag System" as a result many clients who did not need residential care were placed in ICF/MR's, ICF/H's and ICF/DD's.

2. Community Me-Too Phenomena - As increased dollars began to flow to improve the quality of care for the profound mentally retarded, the medically at risk, the severe behavior problems, and the "other developmentally disabled", the unserved and underserved then the parents and community programmers began to clamor for some of the pie. In a very short time ICF/MR's less than 15 sprung up across the nation serving clients who would never have been admitted to the large residential facility. Somehow the parents and programming professionals in the community expect that 97% of the mentally retarded who were never included in the intent of the original Title XIX amendments to be served with the few dollars that are available. With the Title XIX waiver and application of the waiver every state began to try to get a piece of the pie, and somehow hope the pie would get larger. In fact then we have developed a system that increases dependency of clients under a guise of developing independency in a waiver system designed to prevent placement in more restrictive settings. Although Title XIX eligibility requires no substantial gainful activity (SGA) for a year there are clients in community homes fundedby ICF-MR's who are in supportive or competitive work. Therefore we are serving more than the 3-4% of the mentally retarded that Title XIX was originally designed for.

In summary I belive that Medicaid financing services should be limited to "most-in-need-clients" and that LRE, size, and generic services should be reexamined to provide for the quality of care for the (MIN) to 3 to 4% of the of the mentally retarded clients. I believe that Congress with the states should formulate a different, innovative, and more appropriate funding system for the large numbers of developmentally disabled who do not, and will not meet the Substantial Gainful Activity requirement.

Sincerely,

Maurice Dayan

Maurice Dayan, Ed.D.

MD:lg

Statement presenting our views to
the Finance Committee examining
MEDICAID FINANCING OF SERVICES FOR
DEVELOPMENTALLY DISABLED PERSONS
for inclusion in the printed record
of hearing held in Washington, D.C.,
on SEPTEMBER 19, 1986

Submitted by:
Terrence R. Turner
Chairman, Legislative Committee
Parents Association
Hammond State School
501 State School Road
Hammond, Louisiana 70401
September 25, 1986

Note: This statement submitted
in lieu of oral presentation
pursuant to instructions
contained in press release
of August 7, 1986.

Introduction

Press release of August 7, 1986, announcing hearing on Medicaid Financing of Services for Developmentally Disabled Persons cites substantial increase in funds for intermediate care for the mentally retarded over the last 10 years. It would appear that major factors contributing to increase in both the total and unit costs were inflation, accommodation of more individuals needing ICF/MR facilities, and increase in the quality and quantity of services provided the residents. The increases also reflect the fact that, until fairly recently, ICF/MR units were the only residential facilities available to persons with mental retardation.

Impact of Group Homes

Residence in group homes is an option not always available. Over time, movement of mildly retarded persons from ICF/MR units will reduce populations of the larger facilities. However, it should be emphasized that there will always be a need for larger facilities to accommodate the severely and profoundly retarded persons, many with a mental age as low as 18 months.

There is no question but that some persons with mildly mental retardation who are now in ICF/MR facilities would be better served in group homes, and sufficient funds should be made available so that all persons in this category are given the opportunity to live in properly operated and supervised group homes.

Providing the Most Appropriate Setting

The philosophy of some organizations. such as ARC-US, and proposed legislation, such as Senate Bill 873, entitled the "Community and Family Living Amendments of 1985," introduced by Senator John Chafee, is that large facilities are no longer needed--that all mentally retarded persons, regardless of their degree of disability, should be mainstreamed. There is substantial opposition to this position coming from some local ARC chapters and, more importantly, from parents of severely and profoundly retarded children. (Attached as part of this testimony is statement outlining our position on this matter.)

The most appropriate setting for a person has been defined as that which provides the "lease restrictive environment." What is the "least restrictive environment" depends on the nature of an individual's disability. We have seen excellent group homes in nice neighborhoods whose residents are benefiting from mainstreaming. Most of the residents are only mildly retarded, with some holding jobs. For them, group homes provide the least restrictive environment. Contrast their situation with people with an exceedingly low I.Q., many of whom are non-verbal, without self-help skills, and with some having more than one disability (e.g., blindness, deafness). These people require 24-hour attention and the ready availability of medical and nursing care with the sophisticated equipment that goes with these things, which are beyond the capability of small community homes. For them, only large, fully staffed and equipped facilities can provide a least restrictive environment.

The Cost Factor

Early on, contention of those opposing large facilities was that institutional care is more costly than community-based residence care. Little in the form of documentation has been offered in support of this position. What data has been presented is obsolete; moreover, the institutional costs reported inevitably include the full spectrum of services offered by large facilities, while reflecting for the small units only the cost of housing, food, and live-in staff. This is comparing apples with oranges.

Despite this obvious distortion, some studies have shown that institutional costs are still lower than those for small homes. Given the economy of scale principle, large units should have lower unit costs, a factor commonly overlooked by those who would insist that group homes are less costly than large facilities.

The fact is that no reliable cost data is now available. Perhaps, in any event, cost should not be a primary issue in providing services to developmentally disabled people. But, if cost is to be considered, a complete, objective study should be made by an independent group, giving full consideration to the kinds of services available at both types of residencies and the number of cost units to which overall expense can be allocated.

What about large facilities?

Those who would eliminate large facilities would probably classify the Hammond State School as undesirable, chiefly because it has more than 600 residents. Wouldn't this be a place with bars on the windows and children lying about in crowed wards? The answer is a resounding "No." The fact is that a devoted staff and an active Parents Association have joined together to make the school's environment as close as possible to a home-like atmosphere. This is true of similar facilities across the country.

Hammond State School is located about 60 miles outside New Orleans on 100 beautiful woodland acres donated by a private citizen. It enjoys an excellent reputation, thanks to sound, compassionate management, the cooperation and participation of the Parents Association, a fully staffed nursing and medical unit, and a modern physical plant. The school is the official domicile of the Louisiana Special Olympics, housing the special Olympics staff. It was partly responsible for the International Games held at the Louisiana State University in 1983. The school's Music Therapy Group has appeared on numerous radio and television programs. A highlight of this activity was a visit to Washington, D.C., when they entertained the President in the White House.

Residents are regularly entertained with picnics, trips to State and Parish fairs, football, and other athletic contests. Chaplains provide for their spiritual needs.

Over the years, the Parents Association has worked very closely with school officials to provide the best possible living environment for the residents.

Contributions included $67,000 toward construction of an all-faiths chapel, construction of gazebos throughout the campus, financing of an annual Bible School, sponsorship of Christmas parties and parades, purchases of television sets and other appliances, providing materials and furnishings for the gymnasium and swimming pool, subsidization of the Industrial Therapy Program, and numerous other activities. (A partial list is attached.)

Critics of large facilities ignore the fact that they must maintain stringent standards required by State and Federal agencies.

Conclusion

We maintain that both types of residencies are necessary--they are not mutually exclusive. Some persons in large institutions do not belong there. These people are capable of functioning in the mainstream and should be given the opportunity to live in small community settings, even if the cost proves to be greater than that of large facilities. On the other hand, many, if not most, of the persons now in large facilities need the 24-hour care and attention that can only be provided by stable, fully staffed and equipped operations that are responsive to needs peculiar to the severely and profoundly handicapped.

As to costs, no really definitive data is currently available; but, on the surface, it would appear that institutional costs are less than those for small community homes. But, the primary factor should be assurance that persons with developmental disabilities will be able to live in the least restrictive environments.

Submitted by:

Terrence R. Turner

Chairman, Legislative Committee

Parents Association

Hammond State School

501 State School Road

Hammond, Louisiana 70401

September 25, 1986

OBJECTIONS TO COMMUNITY FAMILY LIVING AMENDMENTS (CFLA) OF 1985
(S873 and HR2902)

By: Terrence R. Turner, Parents Association, Hammond State School
MAILING ADDRESS: 6134 Orleans Avenue, New Orleans, Louisiana 70124

1. If passed in anything like their present form, these bills, which essentially are duplicates, would spell the end of large-scale facilities now providing complete training, medical and other services on a 24-hour basis to persons with mental retardation. This would be accomplished by diverting 85% of Medicaid funds from such facilities to small "community living" units serving nine to ten persons (Units of up to 15 persons would be "grandfathered" in).

2. That some residents of large facilities would be better served in properly operated community homes is not questioned. What makes the proposed legislation objectionable is that it stereotypes the retarded persons, wrongly assuming that all such persons should be mainstreamed, regardless of the degree of retardation. Persons who are severely and profoundly retarded require the 24-hour attention, including in-house medical and nursing care, that would be beyond the capabilities of small community homes. Mainstreaming these people would be at their considerable peril. We are talking here of persons with mental ages as low as 18 months.

3. Rate of fund diversion - 85% - is highly arbitrary, bereft of any needs studies or other documentation. It would make more sense if the 85%-15% allocation were reversed, because most of the residents of large facilities are severely and profoundly retarded and it is highly likely that at least 85% of the funds would be needed to serve these persons. But any unsupported percentage allocation makes little sense.

   The 85-15 percent provision represents a major flaw of the Bills. A more reasonable approach would be a review of each resident in a large facility by an interdisciplinary team, including the resident's parents. Where a consensus is reached that an individual would be better served in a community home, he would be transferred, with Medicaid funding following him. Possibly this procedure is already available under the waiver system or could be made available by extension of the waiver provisions.

   It should be mentioned that ARC-US, a staunch supporter of the Bills, feels that all persons with mental retardation, even the severely and profoundly retarded ones, should be mainstreamed. Their position is that any percentage (such as 15%) allowed for large facilities is done so strictly for political reasons. It is indeed unfortunate that an organization that has done so much for the retarded citizen will not accept the fact that large and small facilities are not mutually exclusive - both are needed. (Fortunately, the ARC-US ironclad position on this issue is not shared by all ARC state and local chapters, and certainly not by the majority of parents of severely and profoundly retarded children.)

4. Many parents are concerned over the stability of community programs. Article in Mental Retardation (Volume 23, No. 3) published in June 1985 by the American Association on Mental Deficiency reported on a study made on the stability of residential facilities. This study, supported by a grant from the Health Care Financing Administration of Health and Human Services, found that only 62.3% of facilities serving one to six residents in 1977 were still in existence five years later. During the same five year period, 70.1% of facilities serving 7-9 residents in 1977 were operational in 1982. Survival rate increased as size of residences grew larger with 99.3% of facilities with 500 plus residents remaining.

   Relocation of persons with severe and profound retardation would be both illogical and inhumane. Effect on the individual would be traumatic and doubly so should he be transferred a second or third time because of dissolution of or rejection by a small home unit.

5. The "grand and noble" experiment of the early sixties which moved people from mental institutions back to their communities with disastrous results should give pause for thought to those pressing today for mainstreaming all persons with mental retardation now residing in facilities - both private and public, with more than 15 residents. Many of the mental patients mainstreamed comprise today's street people.

6. The Bills would largely eliminate discretion within the present program which allows states to define client eligibility and the types of services to be delivered within the context of their own programs, policies and service system needs.

7. The misguided notion that small (with regard to residences) is always better seems to underlie philosophy of the proposed legislation.

8. The Bills ignore requirements for freedom of choice as contained in the Social Security Act. They ignore the need for varying levels of services reflective of a resident's condition. They would lead to litigation from disabled persons, their families and guardians who are currently satisfied with the quality of services received in both public and private facilities.

9. State operated facilities would not be the only ones adversely affected by this legislation. Many private schools which rely heavily on donations to cover both operating and construction costs would also be negatively impacted. Despite the phase-in time period provided by the Bills, passage of the Bills would tend to eliminate this important revenue source. Contributors would hesitate giving to a facility whose future is limited. The threat of liquidation would also adversely affect morale of the staffs of large facilities. Many dedicated persons would be impelled to leave their chosen careers.

10. As acknolwedged by Senator Chafee himself, reaction to his S873 has been overwhelmingly against it.

11. Large facilities must satisfy high standards set by federal and state agencies which are constantly monitoring them.

12. In their emphasis on need for "community living" proponents of the legislation overlook the fact that most large facilities provide communities - complete with chapels, recreation facilities, attendance at local sports events and other features that make for a community setting.

The following are some of the accomplishments of the Parents Association since it was organized at the end of 1964.

Our first project, financing a brightly painted, wooden fence for a playground area, used by the smaller, ambulatory children. This has since been relocated and replaced with a more durable metal fence.

The next major undertaking was buying the colorful tractor train and coaches, that still give so much pleasure to the residents, as they ride around the grounds and in various parades in the sourrounding areas.

Through the years many different types of picnic tables and benches have been purchased and placed around the grounds for the convenience of the residents and their visitors.

Funds were supplied for the finishing materials and furnishings for both the Gymnasium and Swimming Pool.

Needed materials were purchased to build the boat pavilion, near the gymnasium.

To protect the residents and their visitors, from sun and rain, funds were given to build the gazebos, that dot our compound.

The Industrial Therapy program was able to be started because of our ability to subsidize this activity.

Much needed linens were supplied, during some of the past linen shortages.

Our All Faiths Chapel Building Fund raised $67,000.00 in addition to the $100,000.00 that Mr. Billups contributed. This enabled us to build and completely furnish our Chapel and offices, in a matter of four years.

Our annual vacation Bible school, organized by Brother T. V. Owen, is financed from the Chapel Fund.

Since building the Chapel we have improved the outside by creating a beautiful little patio between the Chaplain's offices and the Prayer Room. We also changed the lighting system and now have a much brighter and prettier interior. Safety glass was installed and a complete sound system that can be used in and out of the building was purchased.

The Chapel Fund has paid the cost of fencing in our Cemetery, erecting a lovely wrought iron entrance with the school's name and also build a beautiful, granite/monument, in honor of those residents who are buried there.

Christmas is beautiful at the school. This is a time of great activity for the children, staff, parents and friends. A Christmas parade is organized and travels the whole campus so that all residents can view and enjoy the event. Christmas parties are held in all areas with 22 Santa Clauses the center attraction. Christmas morning all residents who are unable to be at home, receive a special gift. The staff members are also remembered with a small Christmas memento. This program has become such a tradition that all the residents look forward from one year to the next for this season.

Through the years we have supplied such needed items as washers, dryers, air-conditioners, T. V.'s, electric fans, wheelchairs, electric shavers, a kiln for ceramics, C. B. radios and a special lawn mower for the play areas.

We have been able to underwrite the publication of the Choir's first album and also generously contributed to their Washington trip.

Every year we financially assist in the Easter Program.

We have added to and accumulated funds to provide two Station Wagons and a Compact car for the Social Service Department. These are used to transport our residents to the various parts of town that require transportation.

We established a visual record of our past superintendents. Pictures of Mr. E. Roy Rogillio and Mr. Edgar Loe Morgan, were made from small photos and installed in the lobby of the school.

Our Legislative Committee keeps in close contact with our State and Federal Legislators. They have been able to insure that the school would not be without natural gas during the energy crises. They were instrimental in having the school's budget increased, when more direct care was needed for the children. They also petitioned the Governor for his aid in securing housing and financial help to obtain the necessary medical personnel that was needed. Our political involvement is a most important activity that requires the support of all our parents and friends.

We are constantly trying to make the public aware of the Hammond State School and educate them to the needs of our children.

We have created a special fund to furnish a "Works Activity" building that the State has built for the school.

Seven pianos were bought to be able to have them in all areas, so that the residents could be entertained with music and song.

We have paid to have a train room built to house a complete collection of electric trains, that was given for the enjoyment of the residents. This collection will cover an area of 64 square feet.

An area for outdoor picnics, has been developed, this means shelters, tables, benches, barbecue pits and water facilities. This we feel is important as it will provide a space where private gatherings can be had, right on the school grounds.

A very generous contribution was given to the "Walk Down Highway 1" promotion to raise funds for the International Special Olympics.

In answer to an emergency plea from our Superintandant, funds were made available to purchase an auto clave cart to complete the unit provided by the state.

Many problems and needs within the Hammond State School have been solved by the Parents Association and the School, working closely together, for the benefit of the residents. This is the reason for our Association, first for the good of the children, their welfare and protection, secondly to aid the school, our parents and guardians.

Re: MEDICAID FINANCING FOR DEVELOPMENTALLY DISABLED PERSONS.

To: Committee on Finance
Dirksen Senate Office Building
Washington, D.C. 20510

As a parent of a profoundly retarded forty year-old son, I am very much concerned over the possibility of the change in Medicaid reimbursing policies which may result in the placement of the severely brain-damaged in settings which would be detrimental to their welfare.

However well-meant the dream of mainstreaming all retarded may be, it does not take into account the real needs of individuals like my son who thrives best in a structured environment such as that provided by the state school where he has been for the past 12 years. Indeed such a setting which has been designed with the limitations of the severely retarded in mind and which provides for their total needs -- medical, physical, recreational, educational -- on one campus is a much less restrictive environment than a "normal" group home in the community would provide.

I know from experience, not theory, the problems and frustrations of keeping certain types of the retarded in a normal home. Everything must be kept locked -- doors to outside, phonograph, refrigerator, deep freeze, knives, scissors, etc. I never let my son out of my sight unless he is locked in his room as there are no other eyes to watch and see that he does not get into trouble. This I can do for a limited period of time without becoming too "burned out" because he is my son and I love him dearly. I do not believe any community provider would have the patience and stamina to keep him in a home permanently, but instead either he or his "foster parents" would be changed fairly regularly, upsetting the routine which he needs. Change is very upsetting to the brain-damaged. They want a routine which they are used to and which does not vary -- not a "normal" home.

I am speaking personally because a parent who has had her child in both situations for a number of years can offer a different viewpoint from a professional whose viewpoint is based on a dream theory.

If all the retarded are placed in community, the ultimate aim of some, and the institutions and their programs phased out, it will be too late to rectify the damage to that segment of the retarded most in need of institutionalization. (This word itself is a "turn-off", connoting as it does the many poorly run institutions of the past whose demise no one laments.)

page 2.

I recognize the need for community group homes for the mentally retarded appropriately placed there; indeed there are three such in my community in which I have an interest. We need more, but placement should be made only when such a setting has been determined to be the most appropriate for the individual and is not based on an arbitrary quota. Shouldn't the money follow the child, instead of vice-versa?

I hope you will give consideration to this viewpoint and take a cautious approach to any action which adversely affects those most in need of services appropriate to their needs.

Most sincerely,

Lucile P. Hands

Lucile P. Hands
600 Pennsylvania Avenue
Minden, La. 71055.

Minnesota Coalition of Parents and Friends for Community Residential Services

A Position Statement on the ICF/MR System
Submitted to the Subcommittee on Health of the Senate Finance Committee
September 19, 1986

On behalf of the Minnesota Coalition of Parents and Friends for Residential Services I appear before Senator Durenberger's subcommittee on Health of the Senate Finance Committee today for the hearing convened by Senator Packwood.

My name is Galen Pate and I am the father of Elizabeth, age 19 years. Elizabeth is a resident of Dakota's Children, an Intermediate Care Facility for the Mentally Retarded for 48 people in West St. Paul, Minnesota. When Betsy was thirteen months old, she was diagnosed as having cerebral palsy, profound mental retardation, and a seizure disorder. She required, and continues to require 24 hour a day total care.

Because of the level of care Betsy requires, our family was not able to care for our daughter in our home. Between the ages of three years and six years, Betsy lived in both foster homes, and board and care facilities--both totally unacceptable to our wishes for our daughter to develop her potential and to have close family ties.

In 1972 our family, together with several other families took the position that our children had a right to live in their own community. There were few alternatives and little hope for us at that time and although the difficult decision had been made to look for care outside our home, the added hardship of separation and the pain of not being part of our child's development, led us to develop the concept of a group home in our own community.

Our original wish for Betsy was a small home for six people but in the early stages of planning, it became evident that the cost for meeting the needs of a profoundly handicapped person in compliance with state and federal regulations of the Medicaid Program, would require that the home be designed on a much larger scale, be staffed with a higher staffing ratio, and costly physical plant requirements be included.

That was in 1973. Today, in 1986, the cost of meeting the needs of mentally retarded people requires the same analysis in cost containment. Recent federal legislation proposes to limit the size of community facilities to 15 people or less if federal financial participation is to be received. While we applaud federal legislation which addresses the living conditions of people who are handicapped, our experience strongly suggests that it is cost prohibitive for a person needing twenty four hour care, including nursing or behavior intervention, to be served in small settings. The Minnesota Coalition of Parents and Friends for Community Residential Services, many of whom worked to develop community residential facilities, now represents even more parents who are concerned that specialized cost and program effective community Intermediate Care Facilities for people who are mentally retarded are being considered for extinction. We believe the presently embraced size only criteria for existence has not been tested as a valid measure and in fact is directly contrary to our experience in Minnesota.

Parents and friends who are members of this coalition have worked tirelessly to develop effective specialized services for their family members who are severely and profoundly mentally retarded, who are medically fragile, and who may have significant behavior management needs.

The system needs to be expanded in a planned and thoughtful manner so that the quality of care currently available to our children is not compromised through a rush to reduce the size of the facility or the size of the federal Medicaid budget. The range of service options needs to be expanded, not limited, so that our children and all other children who will likely follow them continue to have an effective array of choices available.

What Betsy would be today and what her family would be without the services provided by the Medicaid Program is alarming to ponder. The availability of funding for services which promote her developmental growth has enabled her to progress beyond the greatest expectations of her family. She continues to achieve new developmental milestones through the efforts of trained professionals who work with her in the ICF/MR. These milestones can be shared daily by her family for we are an integral part of her life. The ICF/MR facility gave her the options she never had in the foster home or board and care home and based upon the proposals we see and hear, would not have been possible in the so called new smaller settings.

As parents, the Minnesota Coalition of Parents and Friends for Residential Services are concerned about the future for our children. Over the years we have believed that no single model of service is best for all people and that the freedom of choice is a right we want for our sons and daughters. As active volunteers and members of the Boards of Directors of the organizations represented in the Coalition, we are concerned about the future quality of life provided. As business people in the community, we are concerned about the economic impact of proposed legislation for the ICF/MR system that limits size, creates more paperwork, increases regulations, and ultimately escalates costs to the taxpayer.

We do not want to see a system strongly developed in Minnesota for the past eighteen years arbitrarily changed through federal mandate which would limit size and funding.

Our highest priority is the provision of the best care possible for our children. We emphasize service in the least restrictive environment and insist that a broad of array of services be available, regardless of the living arrangement. As diversity is necessary in the education of the American public, so is diversity in the care of our children.

We do not want our children to be burdens to the taxpayer. However, it is often beyond the emotional, physical, intellectual, financial, and other resources of most families to care for our children at home. We support the establishment of quality control in the field of care for the mentally retarded. An important, but by no means the only aspect of quality control is the cost of care. The cost of care can be most easily calculated in financial terms, but if family disruption, divorce, and emotional illness among members of the immediate family are the toll of caring for our handicapped children at home, some other costs must be considered.

We strongly endorse a role for federal and state financial support for the care of our children who are mentally retarded, which has come to represent an entitlement similar to the right to protection against crime, hunger, and disease. The distribution of federal financing is presently inequitable and must be improved. Progress in the field of caring for persons who are mentally retarded, however, is ideally made "from the bottom up" -- from meeting the needs of individual persons through community facilities rather than by governmental fiat.

On behalf of my daughter Betsy and the Minnesota Coalition of Parents and Friends for Community Residential Services, I strongly urge Senator Packwood, Senator Durenberger, and the Senate Finance Committee to consider the positive benefit of the Medicaid Program. The ICF/MR model is a proven system which has progressively developed through years of experience. It is crucial that progressive development continue and that options be created within a fiscally prudent manner. The Medicaid Program has largely been responsible for raising our children's services above the level of custodial care and warehousing which formerly existed. We strongly support systematic long range planning with adequate flexible financial resources to assure a quality of life for all citizens who are handicapped by mental retardation.

This Fort Worth State School Parent gave this testimony to the Texas Board of MHMR on June 14, 1985, when the Board met at FWSS.

June 1985

I am Mrs. Edward Muse, and have a son who was a resident of the Brenham State School for eight years and for the past three and a half years has been a resident of the Ft. Worth State School.

I feel that Edward has been well cared for and is always ready to return to his dormitory after a visit home. This is reassuring to me, since he has limited speech and cannot tell me his problems. I am one of the many parents who prefers the large school rather than a small community home, and I sincerely hope that placement of the first 279 clients in community settings as directed by Judge Justice give our institutions an opportunity to improve services rather than be down-graded by diminishing funds and lack of interest of the administrators.

This school has a spacious campus with a park-like setting, and it is to this point that I wish to speak.

Questions by a visiting member of the Texas Senate and recent publicity about the plan to review all state property to see if it is being used in the most effective manner concerns us at the Ft. Worth State School. The land for the school was given by the Amon G. Carter and the Sid W. Richardson Foundations, and the records of the Richardson Foundation furnish this information from which I quote:

"The purpose of these grants is made quite clear in the letter addressed to Mr. Joe K. Butler, Chairman of the Texas Board of Mental Health and Mental Retardation, on June 7, 1972. This letter, signed by the Presidents of the Carter and Richardson Foundations, reads, in part, as follows: "It is understood and agreed by, and between Board and the undersigned, that our conveyance to the above described property will be made by special warranty deed to Board as, if, and when a final appropriation of funds has been made to Board for the construction of a school for the training of mentally retarded persons on such land.

It is the intention of this letter to evidence the promise of the undersigned to acquire and then to make a gift of said land to Board, conditioned upon a proper appropriation and allocation of funds to be made by the state of Texas and/or the Federal Government before the end of 1973 to cover the cost of erecting a suitable school on said lands."

I feel that these two Foundations would consider it a breach of faith if any part of this property were sold and that they would vigorously oppose anything of this nature.

Those of us with children in the school regret the complex of apartments recently built to the north, and we are grateful for the land beyond our perimeter road which prevents this type of development from coming closer. Many of us feel that our children have a freedom here which they could never have in a small home in an established neighborhood. This land bordering the perimeter road could be an excellent location for small group homes with the school gym, hydro-therapy pool, infirmary and occupational therapy resources at hand. I wish this type of service on campus was being developed by the M.H.M.R. Department as has been done in other schools.

DALLAS TIMES HERALD, Friday, Feb. 7, 1986

Parents of retarded fear school cuts

By CHARLOTTE-ANNE LUCAS

Staff Writer

ARLINGTON — Judy Craig kept her severely retarded son at home for 21 years, "caring for the needs of an infant in the body of an adult," before coming to the anguished conclusion that he would be better off in the Fort Worth State School.

There, she said, he is protected, looked after and stimulated to develop behavioral skills in a way she could not be at home.

But like some other parents of mentally retarded youths, she is worried that a proposal by the Texas Department of Mental Health and Mental Retardation will push him out of the school's environment and into a community center.

At a hearing on the proposal Thursday, Craig and dozens of other speakers railed against the department's six-year plan to move the some retarded residents to community centers, which awaits a decision by the 1987 Legislature.

"We don't want our state schools reduced," said Craig, who spoke for the Fort Worth State School Parents Association. "On the contrary, we want them expanded."

Craig argued the patients are in the state school "because it is the very best place for them" and said proposals to move as many as 20 percent of the state school population into community-based centers by 1991 are based on "reckless estimates of the potential productivity of severely and profoundly retarded clients."

Endorsing the department's plan, Diana Fricke of Fort Worth with the Texas Planning Council for Developmental Disabilities, said many retarded people can receive better care and have more freedom in the community.

Although many of the parents said the local centers could provide necessary treatment for mildly retarded people, they said discharging some patients could have disastrous results.

Dorothy Bridges, the Fort Worth mother of a 24-year-old state school resident, said that on a recent visit to the school, she witnessed a violent outburst by one resident that took seven staff workers to control.

"I would not want one of these violent clients to be my neighbor," said Bridges.

"I know that sounds terrible for a retarded parent to say, but I've seen a lot of people get hurt by these clients," she said.

Barbara Harris of Dallas said she is afraid that if the population of state schools is diminished too much, it could mean the loss of even more federal funding and the eventual closing of the school where her daughter lives.

"I don't want my daughter out there where they don't want her," said Harris.

"You certainly shouldn't be moving the retarded into small spaces and into neighborhoods where they're not wanted. ... I want her to live in a safe place where she's not ridiculed for her handicap."

The hearing was the sixth of seven scheduled across the state to solicit comments on the six-year plan.

new directions

National Association of State Mental
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JULY, 1986 VOL. XVI, NO. 7

RUTH E. KATZ, EDITOR

Researchers Focus on Instability of Residences

In a preliminary survey of 596 community residential facilities serving individuals with developmental disabilities, it was found that between 1982 and 1986:

- 27 of the facilities had gone out of business;
- ownership had changed in 72 facilities;
- 67 facilities had changed addresses;
- five facilities reported serving a different client population.

These findings are among the early results of a current study of the stability of the MR/DD community residential facilities. Human Services Research Institute (HSRI), of Cambridge, Massachusetts, undertook this project to respond to "a significant, but as yet undocumented concern" about the stability and permanence of community residential services.

The continuity of community residences is threatened by several factors, including variable interest rates, inflation, increased regulation, declining public support and economic recessions. As the system becomes less stable and predictable, other negative consequences are likely to follow, such as declining confidence among parents of persons with developmental disabilities, lower client functioning levels and staff burnout/turnover. In fact, staff perceptions of instability resulted in a 75 to 100 percent turnover rate among relief staff in one state.

The objectives of the eighteen-month study, funded by U.S. Department of Health and Human Services' Administration on Developmental Disabilities, include: (a) documenting the extent of the problem; (b) identifying factors that affect facility stability; (c) identifying state and federal policies that may influence the long term viability of community living arrangements; (d) exploring ways of assessing the human and financial costs of instability; and (e) applying the study findings to a particular state to validate the results and disseminate information.

Defining a "change" in a facility as a relocation, a change in ownership, a merger or going out of business, the researchers found that of the 20 states studied in the preliminary sample, the highest percent of change during the four-year period between 1982 and 1986 occurred in California (44 percent) and the lowest was in Georgia, where there was no change whatsoever in facilities. Most of the changes reflect either a relocation of the facility or a change in ownership. Both these occurrences seem more likely in small (1-6 beds) facilities (30 percent turnover), although there are a lot of ownership changes in larger (16-63 beds) facilities as well. Eighty three percent of midsize facilities (7-15 beds) experienced no change. In addition, it is interesting to note that although California was ranked as a "low closure rate state", according to data gathered by the University of Minnesota, the community residential system there is experiencing considerable instability. It may be possible that closure rates are not the best indicator of relative stability of a residential service system, the researchers speculate.

It is anticipated that project findings will be applied to:

- policy development regarding t maintenance of community-base privately-operated intermediate ca facilities for the mentally retarde (ICF/MR);
- policy development in the areas of ove sight and support of community living rangements by federal, state and loc administrators;
- preparation of technical assistanc materials for providers, to assist them remaining stable and retaining staff; an
- development of long term strategies fo ameliorating the problem before becomes a crisis in the rapidly expandin MR/DD community residential system.

Final project materials will be available 1987. For more information on the pro ject, contact: Valerie J. Bradley, Human Services Research Institute, 233 Massachusetts Avenue, Cambridge, MA 02140.

ADDENDUM

TO TESTIMONY SUBMITTED TO THE SENATE FINANCE COMMITTEE

SUBMITTED BY
THE NATIONAL ASSOCIATION OF
DEVELOPMENTAL DISABILITIES COUNCILS

COLLEEN WIECK, PH.D.
VICE PRESIDENT NADDC
CHAIRPERSON NADDC PUBLIC POLICY COMMITTEE
EXECUTIVE DIRECTOR, MINNESOTA GOVERNOR'S PLANNING
COUNCIL ON DEVELOPMENTAL DISABILITIES

September 19, 1986

This addendum provides an executive summary of eight policy papers prepared by the Minnesota Developmental Disabilities Council in response to a legislative request for a plan regarding the future of state institutions.

Let me emphasize that Minnesota has plenty of plans, and some would argue that our state hospital system is overstudied. The problems with planning is that when major stakeholders are not involved, the planning is meaningless. Second, the Legislature can act without planning or can require planning and then not act. The study that we conducted involved all stakeholders and did result in legislative action.

PAPER NO. 1: MINNESOTA STATE HOSPITAL FACILITIES AND ALTERNATIVE USE (BUILDINGS)

The major focus of this study was an analysis of the general condition of the buildings and potential alternative uses of those buildings.

We examined several variables including the years the buildings were built, property size, building square footage, physical condition, plumbing condition, and electrical condition of the buildings.

Generally speaking, 43 state agencies reported to us that they do not save money by using state hospitals for other government uses rather than renting or building other facilities. This is due in large part to the condition and age of the buildings, energy costs, and renovation costs.

Of the 31 institutions reported closed nationwide, none have been purchased by private industry. Over half have been converted to other types of institutions, e.g., corrections, Veteran's, geriatric apartments, college, and religious organization.

PAPER NO. 2: MINNESOTA STATE HOSPITAL ENERGY USE AND COST

Energy consumption in buildings is affected by many factors including original construction features, efficiency of heating plant, severity of weather and type of heating fuel used. Meaningful comparison of energy use at the eight state hospitals was difficult.

We recommended that states should undertake energy conservation measures including: utilization of shared savings contracts; use of alternative fuels; purchase of electricity from wholesalers; separate metering of leased or rented buildings to the tenants; identification of surplus buildings for demolition to eliminate heating costs; and installation of improvements such as summer boilers.

PAPER NO. 3: A PROFILE OF MINNESOTA STATE HOSPITAL EMPLOYEES

The legislation authorizing the study was very concerned about the effects on the employees should a state hospital close. The legislation sought specific information about the employees: What is the projected displacement of state hospital employees because of deinstitutionalization, and what is the extent to which displacement can be mitigated through attrition, retirement, retraining, and transfer?

There are over 5,900 people, including part-time and intermittent employees working at our eight state institutions. Direct care staff are often female. The average wage is $4.00 to $5.00 higher than minimum wage. The length of service averages over eight years, and the separation rate varies by location.

The State Planning Agency conducted a survey of state hospital employees to determine future career choices. There were 26 questions, and 3,154 employees responded to the questionnaire. Regardless of how the question was asked, most employees indicated preference for public sector employment.

States may have to be creative in making early retirement more attractive rather than incur layoff costs. The portability of pensions may also need to be investigated at the state level to encourage transfer of employees rather than layoffs.

PAPER NO. 4: THE ECONOMIC IMPACT OF MINNESOTA STATE HOSPITALS

A large industry such as a state hospital contribute significantly to a community's economy. The smaller the community and less diverse its commercial or industrial base, the greater the impact of any closure or downsizing. Economic impact is not only a function of where employees live and spend their money but also where they work in terms of commuting distance.

Salaries of employees are the most significant factor in estimating community economic impact. The impact changes depend upon the dispersion of employees in a geographic area. Economic impact should not be calculated by multiplying total revenue by a multiplier effect such as "10" because it over estimates true impact.

Since most states have centralized procurement systems, local purchases by the institution are a small percentage of local retail sales.

If institutions are located in rural areas with high unemployment, alternative employment strategies are difficult to develop. Retraining and voluntary transfers of employees should be considered as a preferred economic development approach.

Alternative economic development strategies should not imply "filling up buildings with a newly discovered devalued groups such as people with AIDS, Alzheimer's, or those who are homeless."

Institutions located on prime property may be the first to close since economic impact will be lessened. It may be a wrong reason, but it is often more feasible.

PAPER NO. 5: PUBLIC OPINIONS ABOUT STATE HOSPITALS

A significant part of the study of the state hospital system was the development of a public process which provided Minnesotans with an opportunity to express ideas and concerns regarding the future of state hospitals and the delivery of services to persons with mental illness, mental retardation, and chemical dependency.

This public process involved three major elements:

1. The convening of nine town meetings, one in each area of the state served by a state hospital and one in the Metro area. (Over 5,000 people attended. There were 362 witnesses, and 80 separate organizations were represented.)
2. Soliciting letters from the public and interested parties who would express their views. (Over 433 letters were received.)
3. Receiving calls during a "toll-free call-in" day. A total of 202 calls; 174 favored state hospitals.
4. We also sent a "Dear Colleague" mailing once a month to 1,500 people giving results and announcing meetings.

The overwhelming message of the town meetings and phone calls was to keep the state hospitals open. The letters were split on this issue.

Here are the most frequently heard themes emerging from the town meetings:

Concerns about Patients and Residents:

- The special needs of residents should be the primary concern in planning the future of state hospitals.
- Persons most "difficult to place" because of

severe behavioral, physical, medical, communication, or multiple handicap problems are often served by state hospitals.

Views on Community Programs:

- Individuals have moved out of institutions and into the community. They have improved.

- Community programs (community mental health centers, case management, and community support programs) need more financial support.

Quality of State Hospital Staff and Care:

- State hospital staff and the care provided were described as caring, helpful, dedicated, the best, concerned, enthusiastic, skilled, superior care, warm, professional, and nationally recognized.

PAPER NO. 6: RESIDENTS/PATIENTS

Minnesota's state hospitals exist to serve people with mental illness, developmental disabilities, and chemical dependency. While there are many factors which will influence the future of state hospitals, a very important factor must be the individuals for whom they exist.

The state hospital study also found:

1. In 1960, a peak of 16,355 residents/patients were served in the state hospital system.

2. In FY '84, the average daily population of the state hospitals was 4,006 people: 1,230 people who were mentally ill; 2,182 people who were developmentally disabled; and 594 people who were chemically dependent.

We recommend that states should undertake independent verification of individualized needs and treatments to address those needs.

PAPER NO. 7: THE COST OF MINNESOTA STATE HOSPITALS

There are four parts to the cost report. Here are some highlights from the cost study:

Costs of State Hospitals:

1. Fifteen (15) years ago, the care given in

state hospitals was custodial, and the cost per day was extremely low.

2. Court cases and federal standards resulted in better staffing. Costs increased.

3. In this same period, people with developmental disabilities were moving to the community. Costs continued to increase in the state hospitals because:

   a. The fixed costs increased because of fewer residents;

   b. Remodeling and construction occurred across the United States to meet federal ICF-MR standards;

   c. Staffing increased or stayed level in order to reach ratios;

   d. Unionization of public employees occurred which led to higher salaries;

   e. Inflation had an impact;

   f. The proportion of residents with severe/ profound mental retardation increased as less handicapped people leave; and

   g. Indirect costs were added such as overhead and other state administrative costs in order to maximize federal financial participation.

Costs of Community Residential Facilities:

1. The number of group homes in the community has increased dramatically.

2. The ownership patterns can range from family, nonprofit, profit, chains, or systems. Family operations are the least expensive.

3. Community residential facilities need a standard chart of accounts and improved cost accounting.

4. Community residential facilities include capital items but not day programs or service costs.

5. Community residential facilities now serve all ages and all types of handicaps, but the proportion who are most dependent is slightly lower than state hospitals.

6. Why average per diems shouldn't be compared between state hospitals and community facilities:

   a. Costs vary by type of resident (age, level of independence, services needed, and staffing needed). Children are always more expensive than adults. More severely handicapped people are more costly regardless of setting.

   b. Per diems do not contain the same items.

   c. No standard chart of accounts exists.

   d. No cost accounting system exists.

   e. There are several ways of determining costs which produce different outcomes in cost studies: reimbursable cost reporting; average per person costs; fixed and variable costs; units costs; and needs approach.

   f. In Minnesota, costs vary by geographic location (urban, rural); size (6 or fewer, 17 or more); staff ratios, and special certification.

PAPER NO. 8: OPTIONS/RECOMMENDATIONS

The four options presented in this last report include:

1. Keep all state hospitals open but downsize.
2. Decentralize the state hospitals and begin state-operated, community-based services.
3. Increase efficiency and introduce elements of competition in all state hospitals.
4. Closure of one or more state hospitals.

On page 2 of this final report, we begin with a list of all the conflicting roles. Whenever interest groups discuss what is the state's role, there is a tendency to say, "the state ought to," forgetting that we do not have a blank sheet but rather a complex set of roles including: provide services; supervise services; monitor and license; guardian; defendant in court; employer; negotiator; provider of services to employees in case of closure; cost containment; and maximize federal financial participation.

OPTION 1: Continue operation of all eight state hospitals with staff reductions or downsizing in the mental retardation units.

- The mental retardation population will continue to decline because of the Welsch Consent Decree and the waiver.

Effects on Employees:

- Because all types of staff levels are stipulated in the Welsch Consent Decree, the number of staff who could be reduced could be projected.

- The number of staff to be reduced totaled 644 positions.

- Based on historical experience, there are 1,640 separations because of turnover, retirements, deaths, and resignations. This number includes all employees including part time.

- It is our opinion that natural attrition can be used for downsizing as a first option compared to layoffs. Special exception is made to fill positions for health/safety and for Welsch compliance reasons.

- The next option is to make early retirement attractive through extension of early retirement.

- The final option is to extend the early retirement option and to add medical insurance benefits for people until they reach age 65 years. This option is also less expensive than layoffs.

OPTION 2: Decentralize the state hospitals.

We looked at Rhode Island's approach in beginning state-operated, community-based services. Our state AFSCME group prepared a proposal. The Department of Human Services also created a proposal included in this report.

Effects on Residents and Employees:

- Individuals would continue to move to the community.

- Employees would be allowed to bid on positions in community settings.

- Employees would be covered under collective bargaining and pension plan.

- Retraining would be necessary.

- Space needs would be reduced. Property could be declared surplus.
- The state might incur new capital costs in the community or existing housing could be used.
- Economic impact would be dispersed depending on relocation of residents.

__OPTION 3__: Improve efficiency and effectiveness of state hospitals and introduce elements of competition.

- Management information systems would have to be in place--chart of accounts, resident tracking, etc.
- State hospitals would generate revenue as a function of services rendered.
- Each state hospital would be responsible for program mix, budgeting, marketing, and rate setting.
- No catchment areas would exist.
- Counties and case managers would be responsible for payment of service.

__Effects__:

- Individuals and counties would have choice of using state hospitals at a prenegotiated cost of service.
- State hospitals would still be under the same policies.
- There would be more need for flexibility than civil service currently allows. Employees would be trained and transferred based on need.
- Each state hospital would have control over buildings. There would be an incentive to conserve. (This is a real problem area because the state bonds and every facility is not equal in terms of buildings.)
- Proceeds of sale of property would revert to state hospitals.
- Economic impact depends on skills of state hospitals:
  - rental value would approach fair market value;

- — laundry could be a profit center; and
- — per diems would reflect true costs.

OPTION 4: Closure of the state hospitals.

- It is extremely difficult to terminate governmental organizations. There is little political incentive to do so.

- Terminations are usually accompanied by a budget crisis, and/or an ideological struggle.

- There is a lack of systematic evaluation studies to determine impact of closure.

- Why closure doesn't occur:

  - — guarantees instant, galvanized opposition to the idea;
  - — benefit is minimal and means "fractionally lower taxes"; and
  - — incrementalism forces most programs to grow rather than be terminated.

  Each state hospital was hypothetically closed for purposes of this study, and the impacts were assessed.

Effects:

- Based on past experience, if the state does not have time and money to develop community alternatives, the residents are sent to another state hospital. Consideration must be given to:

  - — what is the home county of each resident?
  - — where are beds available?
  - — do they match what the individual needs?
  - — if not licensed or certified, how much money is needed for bringing into compliance?

- There are several research studies of effects on residents, patients, and families. Results are mixed--changes in mortality, health problems, emotional changes, and adjustment issues.

- In the event of closure, we listed nine separate options for employees (pages 28-29). We also estimated the number of people who would take each option, including listing bargaining issues such as layoffs.

We summarized the research on closure and effects on employees (lowered morale, stress, physical problems, emotional problems).

We summarized the alternative uses of buildings, the cost of closure and calculated by hospital, the amount for severance, health benefits, unemployment compensation, and other costs such as heating, security, etc.

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Executive Director
Sheila Harrigan

Statement Submitted to the

United States Senate Committee on Finance

Subcommittee on Health

on

Medicaid Financing of Services for People with Developmental Disabilities

October 1, 1986

Respectfully Submitted by:

Sheila Harrigan
Executive Director
New York State Association of
Community Residence Administrators

Statement Submitted to the United States Senate Committee on Finance Subcommittee on Health on the topic of

Medicaid Financing of Services for People with Developmental Disabilities

I. INTRODUCTION

The New York State Association of Community Residence Administrators (NYSACRA) is an organization representing 145 private, non-profit agencies which provide community-based residential services to persons with mental retardation and developmental disabilities in ICFs/MR, community residences and apartment programs. NYSACRA offers information, technical assistance, training programs, advocacy and other services. Members of NYSACRA have been an important contingent of residential care providers to the many persons who have been deinstitutionalized over the past ten years and to those who needed long term care outside their families long before the Willowbrook Consent Decree.

Institutions were the primary residential model for developmentally disabled persons for over a century. Fifteen years ago professionals, families of the disabled, and consumer groups provided the impetus for the process of deinstitutionalization. They responded to the deteriorated institutional conditions, pricked the moral conscience of the country and forced justice to assert itself. Landmark court decisions and social leadership have not only changed minds but also spending patterns. The fiscal record of this country demonstrates a commitment toward community services and away from institutional services. By 1984, 11 states achieved spending parity between institutional and community services. In 1977 New York State spent about 12% on community services and was, by comparison, 43rd in the nation. In 1984, New York spent about 45 percent on community services and moved, by comparison of percentage, to 10th in the nation.

II. GROWTH OF COMMUNITY-BASED ICF/MR PROGRAM IN NEW YORK STATE

For those of us who believe in the effectiveness of community services, New York has come a long way. Intermediate Care Facilities for the Mentally Retarded (ICFs/MR) grew out of the deinstitutionalization movement as more severely disabled individuals moved from developmental centers into the community. From 1978 to 1982 the growth of ICF/MR development was enormous. The number of ICF/MR placements increased by 363% during that 5-year period.

Today, there are approximately, 5,250 people being served in small, community-based ICFs/MR in New York State and another 5,325 people being served in non-medicaid funded community residence programs. As of April 1, 1985, voluntary providers operated 420 small ICFs/MR; the New York State Office of Mental Retardation and Developmental Disabilities operated 170 small ICFs/MR. The average number of persons per residence was 8 to 9 people. The residential service delivery system in New York also includes developmental centers, family care homes, and family support services.

Medicaid funding in New York State has provided an important opportunity for people with mental retardation to live in integrated settings in the community and to receive the services they require to fulfill their individual potentials and to live more independently.

III. EFFECTIVENESS OF COMMUNITY-BASED ICF/MR PROGRAM

Medicaid funding has improved the quality of care offered to persons with mental retardation and developmental disabilities. We are proud of the community-based ICF/MR program and believe that it has demonstrated its effectiveness in the following ways:

1) By improving the quality of life of persons with developmental disabilities by enabling them to receive the services they need while living in homes in real neighborhoods and participating in community programs and activites.

2) By providing quality services and treatment; in contrast to the custodial care frequent in many institutions prior to the medicaid program.

3) By enabling persons with mental retardation to embrace their full potential and achieve greater independence resulting in the ability of larger numbers of people to reduce their dependence on government funded programs. Service providers in New York State have experienced the graduation of individual clients from ICFs/MR, to less intensive community residences, to supportive apartments and later to independent living situations. Medicaid financed services played an important role in the growth of these individuals.

IV. RECOMMENDATIONS FOR INCREASING COST-EFFECTIVENESS OF ICF/MR PROGRAM

We believe in the value of medicaid funded services and we have several suggestions which will promote high quality and make the program more cost-effective as follows:

A) Adopt a revised version of the Proposed Rules for Small ICFs/MR.

Overregulation of the small ICF/MR program has resulted in higher costs. Standards compliance expectations have driven us to create a paper industry and not just a sophisticated service industry. Adoption of the proposed rules for small ICFs/MR will begin to address this issue. We welcome HCFA's introductory remarks to the Proposed Rule which point out that the "standards should focus more on the client and staff performance rather than on compliance with processes and paper requirements" and that HCFA is proposing "to revise most of the detailed language of the current standards to give facilities greater ability to administer their programs, while recognizing their widely varying sizes, locations, and organizational structure."

These intentions acknowledge the importance of the growth of clients over the growth of paper and affirm the individuality of small community-based programs rather than the sameness of large institutional-type programs. These concepts are important not only for the design of the regulations but also for shaping of process-oriented interpretive guidelines by which surveyors determine the compliance of a program.

We have several changes to recommend, with regard to the Proposed ICF/MR Rules, which we suggest will improve the cost-effectiveness of the program while remaining sensitve to client-needs.

1) Although the definition provided for active treatment in the Proposed ICF/MR Rules is a good capsule summary, the concept frequently means different things to providers and surveyors. Disputes over the applications of active treatment arise with developmentally disabled persons usually for the following reasons: clients are so severely disabled that they seem to be relatively inactive in their treatment, or clients are so high-functioning that they are too active and self-initiating in their treatment, or clients are at easily acceptable level of responsibleness but are active in unacceptable day programs. As a result, providers of services sometimes devote an extraordinary amount of energy in making the treatment look right in order to maintain worthwhile services for clients. Therefore, we offer the following recommendations that amplify and clarify the revised Federal definition of active treatment.

(a) Active treatment is an integrated program of activities, experiences, or therapies expressed in measurable goals and objectives.
(b) there must be a treatment plan where needs are identified and prioritized by the interdisciplinary team.
(c) The amount of active treatment should be determined by the level of disabilility in the various functional levels identified by the IDT.
(d) Services should not simply be limited to habilitative services but should include activities which are vocational, educational, rehabilitative, medical, behavioral and other areas designed to meet client needs.
(e) The plan of care should be implemented and reinforced in formal and informal settings throughout the entire day, as delineated in a client's activity schedule.
(f) The day program selected and justified by the IDT should stand on its own certification merits.
(g) an ICF/MR client who exhibits extraordinary health problems or behavioral disorders, which interupts or alters the plan of care, should be considered as receiving active treatment.

2) The proposed rules require the physician to participate in the client's individual program plan (IPP). This requirement will most certainly add costs to the program. We recommend that the wording be changed to "a physician shall participate, as appropriate" in order to require the physician's input only in cases of more complicated medical involvement. The rule would also require the provision of physician services 24 hours a day. If this rule can be satisfied by having access to a hospital emergency room, we have no difficulty with this section. However, if each facility must have a physician "on-call" at all times, then we would consider such a requirement needless in most cases and unnecessarily expensive.

3) The proposed regulation requires that the implementation of active treatment be "continuous". We support the concept that interventions and services provided must be implemented at both the day program and the residence. However, we are concerned that surveyors may interpret "continuous" to mean "non-stop"; an interpretation which would be both expensive to implement and harmful to the clients. We suggest deleting the word "continuous" and replacing it with "integrated" so that the IPP is required to be implemented and reinforced in formal and informal settings throughout the entire day, as delineated in a client's daily activity schedule.

4) NYSACRA opposes the use of "conditions of participation" as it relates to the new regulations because a survey team could decertify a facility based on a single visit. This decertification authority is too broad to apply to a single condition of participation.

B) Allow deemed status in the Medicaid program as an option for facilities accredited by HHS approved national voluntary accrediting bodies whose standards are comparable to ICF/MR rules.

Federal ICF/MR Standards were derived from the Standards published by the Accreditation Council for Services for Mentally Retarded and other Developmentally Disabled Persons (AC MRDD). AC MRDD standards focus more on Quality of Life issues and are believed to be more cost-effective than are state Medicaid surveys. The deeming of accredited facilities would reduce Medicaid costs by eliminating duplicative surveys.

V. CONTINUING THE COMMITMENT TO MEDICAID FINANCED SERVICES

Medicaid financed services in New York and other states have greatly benefited persons with mental retardation and developmental disabilities by enabling them to receive the services they require in order to achieve both increased independence and an improved quality of life in the community. NYSACRA supports the continued role of Medicaid in financing needed services to people with developmental disabilities.

We would like to thank the Senate Committee on Finance Subcommittee on Health for this opportunity to submit comments.

TESTIMONY

by

Arthur Y. Webb
Commissioner

New York State Office of Mental Retardation
and Developmental Disabilities

Senate Finance Committee

Subcommittee on Health

David Durenberger
Chairman

Hearing on Medicaid Financing of Services for Persons
with Developmental Disabilities

September 19, 1986

I. Introduction

New York State has a well developed and expansive services system for persons with developmental disabilities. Some 26,000 persons are served in our residential continuum and over 30,000 persons are served in a community-based day program continuum. Since 1975, New York has delivered on its strong commitment to depopulate large institutions. Our developmental centers housed over 20,000 persons in 1975. Today, there are only about 9,900 persons remaining in developmental centers and that number continues to be reduced with the opening of new community beds. Our community residential continuum serves over 16,000 people in supportive and supervised apartments, supervised group homes, family care homes and small intermediate care facilities.

The growth of our community-based system has occurred in large part as a result of federal participation through the Medicaid program. However, the restrictions imposed on the use of Medicaid funds and the uncertainty that has resulted from the Health Care Financing Administration's (HCFA) management of the basic program and home and community care waivers presents a real obstacle to New York's fulfillment of its goal of an expanded and cost-effective community services system.

Mentally retarded and developmentally disabled persons receive services within our continuum of care which go far beyond their medical and remedial needs. OMRDD has found that these people respond best to programming which is developmental, comprehensive and level of care oriented. Such programming should be life-long in nature and seek to enable a person to maximize his or her ability to function through an integrated service approach which includes appropriate levels of vocational, educational and habilitative training as well as medical and rehabilitative services.

II. New York State's System of Care and the Role of Medicaid in Financing the Continuum

First, let me provide an overview of the current MR/DD system in New York State and the future direction we foresee in terms of program expansion. In the early 1970's, great impetus was created to redirect the system away from institution service provision to community-based program alternatives. Pressure to do so was created as a result of civil rights federal court cases, and the initiative was reinforced by major federal statutes which articulated these rights and created new service modalities to better respond to the needs of handicapped citizens. While the initiative was there, sufficient federal funds were not available to support implementation. Only the Medicaid program with its categoric entitlement for the permanently handicapped, provided the potential for federal financial support to any meaningful degree.

New York State utilized this state administered program to further its efforts to return people to the community who had been institutionalized and to upgrade the quality of services for those individuals who remained in institutional settings. We now offer residential services to over 5,500 people living in community-based ICF/MRs. Over 26,000 individuals are served in the OMRDD residential continuum; 62% of these people are Medicaid beneficiaries. We have also elected to include Medicaid funded personal care services as a component of the family care program and are building a similar component into the community residence program. The availability of Medicaid has furthered the development of the day service continuum; OMRDD offers day treatment, which is Medicaid reimbursable to approximately 10,000 substantially disabled individuals who comprise more than 30% of all day service recipients. Without a doubt, the expansion of developmental disabilities services in New York State is directly attributable to the increase in federal financial participation through Medicaid. If this was unavailable, it is conceivable that the system of services would not have moved as dramatically as it has to community-based care. In summary, the Medicaid program has been used in New York State to move the service delivery system away from institutions and toward the community.

While we, as an agency, are pleased by our accomplishments, there remains a major service development task ahead of us. Our efforts to reduce the developmental center population will continue - 4,000 more institutionalized individuals will be placed into community settings over the next six years. At the same time, the energy and administrative commitment that have been devoted to deinstitutionalization must be rejuvenated so that our system can also expand the capacity to serve developmentally disabled persons who have remained at home with their families. This group includes young adults who are being graduated from the special education system and who need vocational training programs. It includes older mentally retarded persons with aging parents who can no longer provide consistent long-term care within the home. It also includes infants and young children who can benefit dramatically from early intervention services which lessen the long range effects of developmentally disabilities. In all cases, it is important for us to provide support services to the families of our clients so that their abilities to continue offering informal care is sustained. As evidence of OMRDD's commitment to this unserved population, we plan by 1991, to serve 9,000 more people in the community residential continuum and to double the number of persons who participate in day programs, which necessitates the development of habilitation and vocational training services for an additional 20,000 developmentally disabled adults.

III. New York State's reasons for not participating in the Waiver Program

There is a substantial unmet need for services to developmentally disabled people. As previously stated, Medicaid played a very significant role in the expansion of services. It is New York State's perspective that if we were to adopt a home and community care waiver, then the same role that Medicaid played in the past, would have to be played in the future. In other words, Medicaid, through the home and community care waiver, would have to serve our purposes in meeting the needs of the unserved and underserved. OMRDD needs to meet the demand for services in a responsible way. Medicaid assisted New York State in achieving that objective in the past. OMRDD would expect the same from the role of Medicaid in the future. However, as HCFA has chosen to interpret the formula used to determine approval of waiver requests, New York State would not have been able to use Medicaid under a home and community waiver program to further its goal to serve new beneficiaries.

What has become clear, as HCFA of the Department of Health and Human Services has progressed in its implementation of the home and community care waiver, is that HCFA interprets the waiver as a cost-containment vehicle. Yes, HCFA wants to encourage lower cost services and the effective use of Medicaid in the home and community-based environment. But through regulation and administrative interpretation, they use the regulatory formula in the waiver to assure that: (1) the average per capita cost after the waiver is less than the average per capita cost before the waiver, (2) the total aggregate cost after the waiver is less than the aggregate cost for services if the waiver services were not available, and (3) most importantly, the number of beneficiaries are limited to persons currently institutionalized or scheduled for imminent institutional placement. In summary, the waiver, as it is currently being implemented by the Health Care Financing

Administration (HCFA), basically allows home and community-based services to only become available for people moving from institutions to the community, or those few for whom an institutional bed has been made available or capital construction has been planned. We do not believe that the institution should be viewed as the system's entry point. The interpretations of the formula creates a fiscal disincentive for states to use Medicaid as a vehicle to expand services to new recipients. This is the exact opposite of many people's perceptions of what the home and community care waiver is intended to accomplish.

If a state's primary goal was to focus strictly on deinstitutionalization, the waiver program is unnecessary. New York State has substantially reduced the census in its developmental centers, in great part through the development of community ICF/MRs. Also, Medicaid has enhanced this system's ability to expand the day program continuum through the addition of day treatment services. Medicaid reimbursable personal care services allow more severely disabled individuals to live in family care homes and community residences. All of these program components have been added through existing options available as part of the State Medicaid Plan.

OMRDD did examine the nature of other services and programs that support families and clients who reside at home or in the lower cost out-of-home care programs that would be needed as the system grew to serve more people. Services, such as home care and home health care, are already Medicaid reimbursable, and New York State must only make decisions on the approach to making these services more generally available to persons with developmental disabilities. Other services, such as respite, family counseling, parent training, and crisis intervention, are generally relatively low cost services that require a high degree of flexibility in service delivery and management. OMRDD believes that existing regulatory requirements of Medicaid programs and the federal requirements for administration of the waiver are rigid and inflexible and may inhibit effective and flexible service delivery.

As part of our analysis of the program components which are necessary to expand the current service delivery continuum, we have reviewed the suitability of the community-based ICF/MR program as one of the residential options available to individuals with developmental disabilities. OMRDD believes that there is a role in the system of care for small ICF/MRs, and that this was the intent of Congress when it created this category of care within Title XIX (Medicaid) of the Social Security Act. We believe the current actions of HCFA, through the use of its regulatory formula, run counter to the intent of Congress to allow small ICF/MRs as a responsible option to large institutions for the care of the disabled.

OMRDD believes that, while the ICF/MR program provides the opportunity for appropriate intensive direct care and professional clinical services, certain federal regulatory requirements result in unnecessary extra cost. Mental retardation and developmental disabilities advocates across this nation have urged HCFA to modify the ICF/MR regulations so as to institute a more developmental and more normalizing concept in the ICF/MR program. In fact, staff of OMRDD have worked, through the National Association of State Mental Retardation Program Directors, with HCFA, on the development of alternative regulations which would do much to both improve the program and to lower cost. As previously stated, OMRDD does not believe that ICF/MRs are bad--quite the contrary. What is needed is an improvement in the federal Medicaid regulatory environment supporting the ICF/MR program. The community care waiver suggests that the remedy for the problems associated with

ICF/MRs is to do away with them. OMRDD, on the other hand, believes that the remedy is regulatory change, and at the same time that the community care waiver was being implemented in many states, New York State was working to solve these problems through regulatory change.

In summary, if the community care waiver is seen as an approach to solve the problems with ICF/MRs, it represents the equivalent of throwing the baby out with the bath water. OMRDD's preference would be to correct ICF/MR problems through appropriate regulatory change that would give states the capacity to better manage this program.

IV. New York's Proposal for Increasing Home and Community Services

We believe that there is a better approach than that represented by the home and community care waiver. We have submitted a waiver request to the Health Care Financing Administration (HCFA) under Section 1115 of the Social Security Act for a demonstration project which would allow New York State to serve an additional 4,000 persons and provide cost savings to the federal government of $325 million over the four years of the project. With this demonstration waiver, New York State could move ahead with it goals for dramatic depopulation of our institutions, assure quality of care for all persons served in our system, and meet the legitimate growing demand for services to persons living in the community.

The proposed project would expand the basic service and eligibility entitlements contained in the Medicaid program for the MR/DD population. This system is currently oriented toward very costly and highly regulated programs. Proposed changes would produce a service system that stimulates cost-efficiency and service appropriateness, provides regulatory standards that promote quality of care and individualized, tailored services, and ensure the capacity to provide services to a significantly greater number of needy and eligible clients at lower per capita cost. Through requested waivers the existing, Medicaid supported long term care system would be transformed to shift costs from Medicaid programs to lower cost Medicaid and non-Medicaid programs.

Requested waivers will allow Medicaid payments for additional home and community-based services while expanding Medicaid eligibility to many substantially developmentally disabled persons who would otherwise not be deemed Medicaid eligible. Vocational services, case management, personal care, in-home care, supportive work, transition to work, clinical services, transportation, and respite/family care services, among others, would be covered under the demonstration project. Essentially, this would make available, as needed, any OMRDD authorized long term care service to the expanded group of developmentally disabled persons.

Cost containment is also a product of this waiver demonstration. All federal Medicaid payments to the State of New York would be based on the number of eligible clients enrolled in the entire continuum of care multiplied by an agreed upon federal per capita fee. However, at no time will the aggregate bill to HCFA be more than the federal base year figure (adjusted each year for inflation) agreed to between New York State and HCFA at the outset of the demonstration period.

We submitted our 1115 waiver request in November of 1985. I wish I could report to you that HCFA enthusiastically embraced this opportunity to demonstrate expanded home and community services and federal savings of $325 million. In fact, we heard in late August that our waiver request was being denied on technical grounds related to the need for a more rigorous research evaluation design.

Despite this initial setback, we have been encouraged to work with Dr. William Roper, Administrator of the Health Care Financing Administration, and his staff to address their concerns about the research design so that an agreement could be achieved that will result in implementing our waiver concepts. Dr. Roper has informed me that he supports our project's direction and concepts as well as the goals we in New York want to achieve.

I am hopeful that these waiver concepts will be effectively demonstrated in New York. Only then can we achieve a stable, protected and manageable system of care that can more adequately revolve around client and family issues and needs. We are committed in New York State to a system of community-based care. Changes can be made in the Medicaid program to formalize the original goals of congressional action. States can then more reasonably expand the availability of home and community-based services to both beneficiaries leaving institutions and those with legitimate service needs living in their home communities while assuring predictable growth in expenditures throughout the program.

Ohio Private Residential Association, Inc.
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[illegible]

Introduction

I thank you for the opportunity to submit testimony. My name is Chris Lohrman and I am the executive director of the Ohio Private Residential Association. OPRA is a statewide association that represents residential providers who serve developmentally disabled children and adults, parents and relatives of developmentally disabled individuals and MR/DD professionals.

It is our understanding that the Senate Finance Subcommittee is examining Title XIX funding for developmentally disabled individuals, the range of services delivered and the type of setting most appropriate for the long term care of developmentally disabled individuals. We understand that you have received voluminous testimony so we have attempted to keep our recommendations brief. Our recommendations focus on means to improve services and hopefully, restrain the rapid escalation of costs for the Title XIX program.

Goals and Principles for the Title XIX Program

In a January, 1986 report to Congress, the U.S. Department of Health and Human Services identified three major principles/goals on which federal funding for developmentally disabled individuals should be based:

1) Developmentally disabled individuals have a right to be integrated into the community.

2) Developmentally disabled individuals are capable of and have the right to grow and develop to be as independent as possible.

3) Developmentally disabled individuals have a right to be productive citizens.

We support these goals and encourage members of Congress to examine the Title XIX program with these principles in mind. We believe that Congressional recommendations should facilitate achievement of these principles. Adoption of our recommendations would promote achievement of these principles and restrain significant escalations in cost.

OPRA's Recommendations

Recommendation (1): We recommend reinstituting the requirement for comparable reimbursement systems, regardless of whether a facility is public or private and approval of each state's reimbursement system by HCFA.

Issue: States currently are permitted to utilize different reimbursement systems for state funded and community ICF-MR programs. This disparity in reimbursement systems has led to significant differences in reimbursement. For example, the Ohio statewide average for small ICF-MR's is 77.02 and $149.60 for state developmental centers. Federal look behind surveys have demonstrated that this tremendous disparity in costs does not necessarily lead to better active treatment.

Recommendation (2): We recommend passage of legisltion that makes the medicaid waiver program permanent.

Issue: States such as Ohio have hesitated too utilize the waiver program because of the uncertainty as to its permanence. We believe that making the program permanent would promote deinstitutionalization and placement of individuals in appropriate settings that are permitted through the waiver program.

Recommendation (3): We recommend that Congress carefully monitor the revision of the proposed ICF-MR regulations to ensure that the proposed medical emphasis is reduced and that the proposed revisions that will unnecessarily increase costs be eliminated.

Issue: HCFA has issued proposed ICF-MR regulations that increase the program's medical emphasis. This will unnecessarily increase costs. Most developmentally disabled individulas do not have significant medical problems. Several other provisions of the proposed rule also will unnecessarily increase costs. We've attached copies of our testimony to HCFA to demonstrate this point.

Closing Statement

In closing, we appreciate the opportunity to submit testimony. We believe that adoption of our recommendations will provide a balance between rational funding and quality services.

R

Re: 5853 & HR 2902 Long Term Care
Mentally Retarded Bill Hearing

Dear Sir, Mr.

I am Vice President Of Relatives & Friends of Clients of White Haven Center which cares for the Retarded who may come from all over Pennsylvania. White Haven Center is a fine well run Institution and we parents want and need it just as it is. We do not want the above bills to be passed through the U.S. Congress. The Proponents of those bills (Florio) H.R. & Chaffee (Sen.) should in my opinion have consulted with us parents of these mentally disabled people who are so terribly helpless. There are no mildly retarded people in state institutions any more but for Gov. Thornburgh and the A.R.C. U.S., Assoc. Retarded Citizens, United States and especially P.A.R.C. want them all out in the community.

We are affilliated with the Pa. League of Concerned Families of Retarded Citizens plus the Parents Network and we are all concentrating on defeating the above bills. These bills want the Federal (medicaid) Funding which goes to institutions and other smaller I.C.F./M Rs. to go to their privately run C.L.A.s(Community Living Arrangements) for the retarded with only 3 patients per home. That is so unrealistic as to defy common sense to the nth degree. These poor souls that have been put out of Pennhurst are mostly all very inappropriately placed. We have a documented report available for any who care to read it. The Pa. Assoc. of Retarded Citizens sent a report concerning the Pennhurst case aftermath that was almost completely false. We have full proof of this fact.

These small facilities that these proponents want the American taxpayer to pay for are not possible because the cost of monitoring them alone would be prohibitive. The smallest that the Dept. of Health & Human Services allows right now is 15 clients. The Federal Standards are high, thank God. These A.R.C. people have now gotten the Wavers. Federal Legislation 2176 through which they wish to amend the existing laws dealing with Medicaid. We of Pa. League are not even given the names and address of parents or the guardians of institutionalized people so we can inform them. P.A.R.C. Assoc. gets them though.

These A.R.C. chapters (state & county) in many cases are the providers. That is definitely a conflict of interest. They have free wheeling & no supervision, then parents and guardians connot visit their loved ones without much notice time, whereas we can walk into the institution with no notice. The campuses are beautiful and the clients can walk around in perfect safety. Volunteers visit and make the clients lives so much happier. These people who think institutions are all bad never go there to see for themselves. They just listen to the assoc. of Retarded Citizens unrealistic propaganda. We are all inclined to look at all aspects of life through our own eyes, we cannot believe that anyone could like institutional living, but so many of these severely brain damaged people cannot tolerate any change in their routine, and an institution that passes Federal Certification is perfect for them. These fine facilities are far less restrictive than any city apartment could ever be.

There is also one more pertinent point I must make. The Assoc. for Retarded Citizens U.S. claims that these poor souls are not sick and therefore do not need to be under a doctors care. How rediculous, since when isn't the brain not a part of the human body and make no mistake these disabled people are brain damaged and their medication must be supervised by M.Ds & N.Rs only. Here in Pennsylvania the other professionals tell the doctors what to do for the retarded of any type. I know nothing about other causes of retardation but I sure know a lot about Aphasia and Autism as my daughter who is 55 years of age almost 56 suffers from this kind of brain damage. She was born dead and then revived but lack of oxygen for too long caused severe brain damage. Those days that was not generally known that such a terrible thing could happen to the brain but the medical profession knows it now and still people are brought back to suffer like this. Now the A.R.C., U.S. and others want to deprive these so afflicted people of their right to proper care.

Pa. Authorities are declaring people competent who are very severely retarded so that they can declare that they have informed consent. These severely retarded adults are receiving Social Security disability checks because of their retardation. How can this state get away with this law breaking. They put these poor defenseless souls out in an inappropriate home which does not meet the least restrictive requirements of all the laws passed for their benefit.

Thank you
Dorothy Rafferty
Vice President "Relatives and Friends
of Clients of White Haven Center"
White Haven, Pa. 18661
Dorothy Rafferty

TWIN COUNTY - GALAX ASSOC.
FOR RETARDED CITIZENS
BOX [illegible]
GALAX, VA. 24333

September 20, 1995

Betty Scott-Boom
Committee on Finance
Room SD 219, Dirksen Senate Office Building
Washington, D. C. 20510

Dear Ms Scott-Boom;

In this time of fiscal responsibility, the importance of Medicaid funding to the developmentally disabled (and in the case of our advocacy group, the mentally retarded individual) cannot be overly stressed.

The Association for Retarded Citizens, Twin County/Galax, has long been concerned about services delivered and appropriate settings for this group and indeed, we have many members who either have worked or are currently working with that population. We realize that the trend lately has been toward de-institutionalization for many mentally retarded persons, and while we agree in principle with that concept, we also are realists who understand that there are many persons for whom the least restrictive setting may be a "training center" which can provide the wide variety of programming (physical and occupational therapy, speech-language pathology, and audiology, educational, recreational, and music therapies) and medical services required on a daily basis for the severely and profoundly retarded. Especially in more rural areas, these training centers are essential as it is often difficult to pay enough, as well as attract persons to a "Country lifestyle", Southwest Virginia, to attract a variety of professionals away from urban areas so that daily services can be available. Of course, well supervised Group Homes and Sheltered Workshops, (Industrial Developmental Centers) are beneficial for the mentally retarded, but in reality, services for the more profoundly retarded persons are not provided because these places are often understaffed and the workshops have production deadlines to meet which force out the retarded in favor of persons with mild retardation, or most often, persons with mental health or substance abuse problems who can meet production quotas. Perhaps the worst scenario for the severely and profoundly retarded is placement from a training center to an adult home, most of which, although supposedly under Social Services Departments, are operated for profit basis out of old motels or in large old homes, and only provide minimum health care and no programming and run by incompetent persons. Truly, the adult homes to which medicaid funds follow a person are the 1990's dumping ground for the mentally retarded. We know of several cases where persons have gone into the community with skills, medical aids(ie hearing aids, special shoes) and needed prescriptions for high blood pressure, water retention, and special diets only to find them later grossly overweight, hearing aids broken or lost or worse-dead batteries, sitting around eating, sleeping, and watching T.V. Lets face reality in that current laws and regulations are properly enforced in the training centers but not enforced in the adult home setting. Lack of supervision and a well structured invironment is allowing retarded persons to roam the streets. This is the result of forced deinstitutionalization caused, in part, by medicaid inspectors when they decertify an individual and threaten the same for an entire facility.

As an advocacy group for the mentally retarded, we are concerned that

[illegible] COUNTY - [illegible] ASSOC.
FOR RETARDED CITIZENS
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adequate federal funds continue to be spent to maintain quality levels of care in training centers where active treatment is a part of a residents program plan and the center is the least restrictive environment for the person. We know that there is and will continue to be a core of mentally retarded/developmentally disabled persons, due to their problems, cannot appropriately be placed in the community no matter how much money is provided. The moderate/mild retarded can be placed in the community and do function well and can make a life for themselves and we heartily endorse programs for them.

A suggestion that our advocacy group would offer is for Medicaid to work closely with the ACMRDD (Accredation Council for Mentally Retarded and Developmentally Disabled) and come up with a set of realistic standards for evaluating facilities serving the mentally retarded. The current scare tactics the medicaid inspectors use should stop, namely, checking level of care, active treatment, and records 'til something is found.

Another suggestion is that stricter licensing, inspection, and programming guidelines for nursing homes, adult homes, group homes be made. Their personnel's skills and training should meet some kind of standards in order to provide individual programs so that the mentally retarded receive all rights and priviliges with normalization and least restrictive environment as their priority.

Those persons who you see on television or in movies, or appear at Committee Hearings, ask for their human rights, but the large group with severe and profound retardation continue to need persons advocating for them. Let's not play political games with them but let's treat them in a humane manner and see that Medicaid offers them a chance to have a happy life.

Most sincerely,

Sue M. Smith

SUE M. SMITH, PRESIDENT

cc to
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PUBLIC HEARING BY THE U.S. SENATE COMMITTEE ON FINANCE

CONCERNING

THE IMPACT OF THE MEDICAID PROGRAM ON THE LONG TERM CARE OF THE DEVELOPMENTALLY DISABLED.

Testimony of The Voice of the Retarded, Inc.

Presented by
George L. O'Donnell, 2nd Vice President

September 19, 1986

Good morning. My name is George O'Donnell. I reside in Milwaukee, Wisconsin. As the parent and legal guardian of a mentally retarded daughter, I have served as a volunteer in the mental retardation movement at the local, state and national level for over 35 years.

I am speaking today on behalf of the Voice of the Retarded, a national organization of parents and guardians of mentally retarded children and adults who reside in public and private residential facilities throughout the country. The handicapped individuals whom we represent are among the 146,000 consumers of the Medicaid services which are the subject of this hearing.

MENTAL RETARDATION

Mental retardation refers to subaverage general intellectual functioning which originates during the developmental period and is associated with impairment in adaptive behavior. For clinical purposes, mental retardation is often categorized by "levels" of impairment, as follows:

LEVEL I represents gross mental retardation. There is a minimal capacity for functioning in sensori-motor areas.

LEVEL II exhibits poor motor development, and speech is minimal. Generally, there is a marginal aility to profit from training. Usually, there are few or no communication skills. ("Trainable")

LEVEL III is able to talk or learn to communicate. However, there is poor social awareness, and only fair motor development. There may be the capacity to profit from specialized education, and the individual usually requires only moderate supervision. ("Educable")

LEVEL IV is able to develop social and communication skills, has minimal retardation in sensori-motor areas, and is often not distinguished from those of normal intellectual functioning capacity until a later age. ("Educable")

From the above description, it is apparent that mental retardation represents a wide area of disabilities which require an equally wide system of quality services in order to adequately address the demonstrated needs.

POSITION STATEMENT

It is the position of the Voice of the Retarded that mentally retarded children and adults should be afforded the opportunity to develop to their maximum potential by means of a high quality, comprehensive and well coordinated system of care, treatment and services which includes, as part of that system, services in intermediate care facilities.

Within this service system, mentally retarded persons, or their parents or legal guardians acting on their behalf, should be afforded the opportunity to choose the care and active treatment most appropriate to the needs of the individual.

Should it be decided to extend the Medicaid program to include a variety of other types of services and facilities, the means whereby this change occurs should not include reductions in, or limitations to, the Medicaid entitlements currently enjoyed by mentally retarded citizens.

FREEDOM OF CHOICE

The principle of freedom of choice has been part of the Medicaid program since its inception. Freedom of choice not only preserves the right of the mentally retarded individual to select initially those services and facilities which are best suited to the development of maximum potential, it also provides a means whereby the individual may move freely within the service system as needs change, whether due to increasing age, progress in reaching the goal of maximum potential or various other factors. To limit freedom of choice to only facilities of a specified size, is to introduce a one dimensional aspect to the program which impacts unfavoribly on those whose needs may not best be met in that dimension.

MAXIMUM POTENTIAL

The Voice of the Retarded is of the opinion that every mentally retarded individual should be afforded the opportunity to develop to the full extent of his or her maximum potential, regardless of the level of disablilty.

In this process, the first objective should be the development of independence; and, wherever possible, complete release from a dependent status. In a rudimentary sense, the initial objective is the attainment of the capacity to dress, to eat, to bathe, to attend to toileting and to perform without assistance other basic personal functions.

The next objective should be to attain a level of productivity commensurate with the capacity of the individual, through specialized vocational assistance and other forms of help, to achieve a meaningful relationship with the community.

In this regard, it should be observed that "integration into the community" involves a process of interaction and communication with others which, by its intrinsic nature, is independent of facility size, or "neighborhood".

Finally, in order to achieve these objectives, the individual, or the parent or guardian acting on his or her behalf, should be free to choose those services most appropriate to meeting the requirements, as demonstrated by the need.

THE COMPREHENSIVE SERVICE SYSTEM

If anything has been learned over the years about developing services for the mentally retarded, it has been the fact that the system of care and treatment should not be limited to essentially one type of service or facility. It has often been observed that relying solely on the large, remote institution failed as a policy primarily because it denied freedom of choice to many mentally retarded persons whose needs were not adequately served in this environment.

Conversely, a requirment that mentally retarded persons be served, for instance, only in facilities of less than 16 beds in size tends to introduce similar restrictions which are disadvantageous to those whose needs require skilled nursing or intermediate care.

Consequently, it has long been accepted by experts in the field that a diversified system of care and facilities is best suited to the needs of mentally retarded persons.

President Kennedy's "Panel Report" on Mental retardation advocated this approach upon its publication in October, 1962. From that day to this, "continuum of care", or as it is more recently termed, a "comprehensive service system", has been the guiding principle for the mental retardation movement. (1)

MEDICAID AND THE ICF/MR PROGRAM

The Federal Register for March 4, 1986 indicates that, "Fifty States and jurisdictions currently cover ICF care; 49 of these include ICF/MR care and serve over 140,000 individuals in over 2911 intermediate care facilities for the mentally retarded." (2)

A recent report published by the Congressional Research Service of the Library of Congress indicates that, of the total of these individuals who resided in public institutions, as of 1982, 57.2 percent were profoundly retarded and 23.8 percent were severely retarded. This is a total of 81 percent, representing some of the nations's most handicapped citizens.

It is also important to obtain some understanding of these mentally retarded citizens in terms of their functional capacities and multiple handicaps.

29 percent cannot walk without assistance;
61 percent cannot dress without assistance;
40 percent cannot eat without assistance;
28 percent cannot understand the spoken word; and
40 percent are not toilet-trained.

In addition, the multiple handicaps experienced by this group are as follows:

12 percent are blind
6 percent are deaf
41 percent have epilepsy
21 percent have cerebral palsy; and
36 percent have an emotional handicap.

In total, over 43 percent are multiply handicapped.(3)

In our opinion, the assertion that most of these mentally retarded citizens would be better cared for in the more "normal" or "least restrictive" environment of the small group home is of questionable validity.

Many of them need constant, twenty-four hour per day nursing-type care. Some of them are in such fragile physical condition that seizures and various medical emergencies are a common occurrence. On site medical assistance becomes a necessity, and is therefore a part of the Federal regulations for the facilities which serve them.

We agree that there are many retarded individuals presently residing in the community who would benefit greatly if additional small, "home-like" facilities were made available to them. Their needs are no doubt best met in that type of environment.

It is our opinion, howvever, that all retarded citizens should not be forced into one mold. There should be a diversity of services to meet the diversity of need.

Finally, we hardly need mention the fact that we feel certain the deliberations of this Committee will not result in a replay of the "deinstitutionalization" disaster of the 1960's, whereby, today, mentally ill and mentally retarded citizens are on the streets of our cities, day and night, devoid of any "safety net" to ensure their proper care, treatment and rehabilitation. We know that all of America never wants that to happen again.

EXTENSION OF THE ICF/MR PROGRAM - SOME CONSIDERATIONS

As noted, body of opinion recently has been developed which maintains that mentally retarded, and other disabled persons who are presently being served in Intermediate Care Facilities for the Mentally Retarded (ICF/MR), could better be served in small "home-like" facilities in the "community".

An opinion has also been expressed that, since the purpose of the Medicaid program, at its inception, was to provide "medical assistance" and "rehabilitation" services for disabled persons, the Medicaid program should be amended to provide for a more diversified system of care, on an "entitlement" basis.

If the configuration of the service system is to be changed by the extension of the Medicaid program to individuals and types of facilities not presently covered, it is the opinion of the Voice of the Retarded that the procedures to effectuate such a change should not negatively impact upon the lives of literally thousands of retarded citizens who are presently covered.

Rather, the extension of the Medicaid program to other types of services and facilities should be allowed to develop in an atmosphere which affords those retarded citizens, or their parents and guardians, as consumers of Medicaid services, the right to continue to select from a comprehensive array of available services and facilities, those living arrangements, and types of care, which are most appropriate to their needs.

THE COST OF COMMUNITY SERVICES

While, as a justification for the redirection or "transfer" of funding from so called "large" facilities to what are termed "community living facilities", proponents often allege that there would be significant cost advantages, no concrete data has been presented in substantiation of this claim.

In fact, Braddock, a strong proponent of the extension of Medicaid funding to other types of facilities makes the following statement in his Public Policy Monograph No. 29, dated June 20, 1986.

"We must also defeat the myth that high-quality care in the community is going to be appreciably less expensive than comparable care in the institution. Community integration must not be based on cost savings. Of course, it is cheaper to pay non - union group home workers less than their unionized counterparts in state facilities; but such a practice only portends a future of high staff turnover and low morale. At the very minimum, over the next ten years, we should press for a doubling in real economic terms of the wages of direct care workers in community settings, and for a 50 percent increase in wages of entry level and experienced technicians in institutional settings." (4)

LEGISLATIVE INITIATIVES

It is apparent that this public hearing on Medicaid has been called partly because, recently, legislation has been proposed whereby Title 19 of the Social Security Act would be amended to include individuals and types of facilities not presently entitled to receive Medicaid assistance. While the Voice of the Retarded supports the concept of broadening the array of services and facilities which would be included in the Medicaid program, there are some aspects of the proposed legislation which, in our opinion, are cause for serious concern in terms of their possible adverse impact on retarded citizens.

There are presently, to our knowledge, three proposals in this area which are being considered by the Senate. These are Senate Bills 873, 1277 and 1948. We would like to comment briefly concerning each of these proposals.

SENATE BILL 873 (5)

Senate Bill 873, the "Community and Family Living amendments of 1985", would amend Title 19 of the Social Security Act to provide Medicaid entitlements for a defined group of "severely disabled individuals".

It is proposed that this covered group would reside in natural homes, adoptive homes or foster homes. In addition, coverage would also be extended to those who would reside in "community living facilities", defined as those of less than 16 beds in size, with an average size of about nine beds.

Senate Bill 873 would reduce, over a period of time, and eventually cap at a relatively low level, the Federal funding presently provided, on a matching basis, for "large facilities", defined as all those over 16 beds in size.

It is alleged that the funds thus "recovered" would then be "transferred" to the "community", where they would be used to develop smaller, more "home-like" facilities. There is, in this proposal, the strong implication, if not the actual assertion, that the entire process would be neutral from a cost viewpoint.

However, the report of the Library of Congress which was previously cited indicates that, as of the fiscal year 1985, the "severely disabled individuals" defined in Senate Bill 873 would create an eligible group, the size of which is estimated to be at least 1,015,000 persons.(6)

If we assume a very conservative cost of $25.00 per day to provide Medicaid services for this group, the total cost of the proposed program would exceed $9.2 billion. This cost figure is substantially in excess of the $4.7 billion noted as the cost of the current ICF/MR program in the press release of this Committee, dated August, 1986 which announced this hearing. There is no way that $4.7 billion can be "transferred" into $9.2 billion.

Also of concern is the fact that this program would require major "start up" costs, because a substantial number of "community living facilities" would be required to accommodate the defined group of "severely disabled individuals".

For instance, the Library of Congress, in the study noted, points out the fact that those persons with mental retardation or related conditions who are served in some form of State licensed residential facility in the United States number 243,669. This figure includes the approximately 146,000 individuals who are presently served in intermediate care facilities for the mentally retarded. (ICF/MR) (7)

Of this total, 179,966 reside in facilities over 15 beds in size. If this group, of "severely disabled individuals", were to be transferred to facilities averaging 9 beds in size, as is proposed by Senate Bill 873, it would be necessary to provide an additional 19,996 "community living facilities" throughout the country.

If the average cost of these facilities is estimated at a very conservative $100,000 each, the total capital requirement would amount to slightly under $2.0 billion.

Again, it should be emphasized that this estimate considers only those with "mental retardation or related conditions". It does not cover the entire group of "severely disabled individuals" defined in the bill. The Library of Congress, in the report cited, states, "As of this writing, there are no estimates available of the total number of persons who would be eligible for, and in need of, services under the proposed amendments or of the optional services States might choose to make available".(8)

In view of these facts, it is our opinion that it would be grossly unfair to thousands of our most handicapped citizens to arbitrarily embark upon a program of systematically reducing their present legal entitlements to Medicaid services without more specific information as to the availability, and the quality, of the services and facilities to which they are to be "transferred".

Consequently, we cannot accept Senate Bill 873 without substantial modifications to correct what we perceive to be some very serious deficiencies.

SENATE BILL 1277 (9)

Senate Bill 1277, the "Medicaid Home and Community-Based Services Improvement Act of 1985", would amend Section 1905(a) of Title 19 of the Social Security Act to provide "home or community-based services" under the Medicaid program without the neccessity of obtaining a waiver.

Is is important to note that Senate Bill 1277 removes the services provided under the present "waiver" program, as contained in Section 1915(c), and places them under Section 1905(a) of Title 19 of the Social Securtiy Act.

By specific reference contained in Senate Bill 1277, the services defined therein are to be provided "without regard to the requirements of Section 1902(a)(1) and Section 1902(a)(10)".

While it is understood that the apparent intention of S.1277 is to perpetuate a program which is judged by some to have been successful in effectuating a "community option" for a number of mentally retarded individuals who formerly resided in "institutions", it should be noted that, often, the waiver program, as presently administered, tends to raise some important questions.

For instance, by means of Section 1915(c) of Title 19, the Congress implemented the "waiver" procedures. The waiver, as it currently applies, contains some important "assurances" which the States must provide to the Secretary of H&HS before Federal funds are to be used for these purposes.

These are as follows:

Safeguards are required to protect the health and safety of persons provided services and to assure fiscal accountability for the funds expended.

Persons entitled to institutional services are to be evaluated to determine the need for such services.

Persons determined to be likely to require institutionalization are to be informed of the alternative available under the waiver program.

The average per capita Medicaid expenditure for services under the waiver is not to exceed the average per capita Medicaid expenditure that the State would have made if the waiver had not been granted, i.e., the cost of community services is not to exceed the cost of institutional services.

States are to provide annual reports on the impact of the waiver program which include data on the types and amount of assistance provided and information on the health and welfare of the recipients.

The apparent intent of the Congress in enacting the "waiver" therefore, was to provide, in effect, an option to persons residing in the community, or elsewhere, whose disabling condition is such that admission to an intermediate care-type facility is indicated, unless means are provided to assist that individual to either remain at home, or to reside in an alternate-type facility in the community.

The proviso was that the per capita cost of the alternate facility selected not exceed the per capita cost of the intermediate care facility to which the individual might otherwise have been admitted.

However, in practice, so far as mentally retarded persons are concerned, the "waiver" program has tended to become a deinstitutionalization program by means of which the States "depopulate" their institutions. In some instances pocedures have been developed, with the cooperation of the Department of

H&HS, whereby retarded persons residing at home have been cut out of the program, and the "waiver" has been applied exclusively to achieving the state's objective of placing retarded persons from "institutions" into the "community".

We would propose that consideration be given to amending Senate Bill 1277 in such a manner that all retarded persons would have an equal opportunity to choose those facilities most appropriate to their needs. We recognize that the apparent intent of Senate Bill 1277 was to provide freedom of choice, but we are concerned about possible interpretations which might be placed upon certain technical insertions which have found their way into the proposed legislation. We would advise that these not be utilized to limit freedom of choice.

SENATE BILL 1948 (10)

Senate Bill 1948, the "Quality Services for Disabled Individuals Act of 1985", would amend the Social Security Act to establish standards for all residential facilities which provide services under Title 19 for developmentally disabled and mentally ill individuals.

Services in all types of facilities would be designed to foster individual development and independent functioning, and a "Bureau of Quality Services" would be established to effectively monitor quality and efficiency in the service delivery system.

In our opinion, senate Bill 1948 embodies many features appropriate to an equitable extension of the Medicaid program:

To insure high quality care, there is a strong emphasis on standards and training of survey personnel.

The covered group is clearly identified as consisting of the developmentally disabled and the mentally ill, both of whom are already defined in existing Federal law.

Federal standards would cover all services and faclities which receive Medicaid funding, including intermediate care facilities, as well as community-oriented living arrangements.

The overall purpose of the Act is to assure that developmentally disabled and mentally ill individuals receive quality services, designed to promote "independence, productivity and integration". In addition, procedures would be developed to monitor the manner in which such services are delivered.

Specifically, Senate Bill 1948 would centralize, within the Department of Health and Human Services, responsibility for quality control of all services provided under Titles 18 (Medicare) and 19 (Medicaid) for developmentally disabled and mentally ill persons.

In our judgement, these provisions tend to make a substantial contribution to a quality controlled, efficient and equitable service delivery system.

However, we have initiated inquiries, to which we are anticipating an early response. These are as follows:

With regard to the monitoring aspects of the bill, it is proposed that a "Bureau of Quality Services" be created. We wonder if this is neccesary, or could the present monitoring structure, under the Health Care Financing Administration, be adapted to these purposes.

Also, we require some clarification as to exactly what standards are to be utilized. It would appear that the present Federal standards of care for intermediate care facilities for the mentally retarded (ICF/MR), adopted in 1974, which are currently undergoing an extensive update and revision, are to be discontinued in favor of entirely new standards. We are concerned as to the overall impact of this proposed change on the Medicaid program.

There are a number of other areas of concern which we hope to clarify through discussion with the proponents of the bill.

However, in the overall, we view Senate Bill 1948 as a constructive proposal which could solve many of the questions presently being raised concerning the adequacy, flexibility and quality of the Medicaid program.

CONCLUSION

In conclusion, we would observe that, in our opinion, the extension of Mecicaid benefits to all mentally retarded individuals who qualify as being in need of "medical assistance and rehabilitation" is commensurate with the original intention of the Social Security act, as stated in Section 1901.

However, the Medicaid program should continue to apply the policy of freedom of choice which has characterized that program from its inception. Certainly, no procedures should be adopted which would single out certain aged or disabled groups for limitations which do not apply to all groups covered under the program.

Mentally retarded citizens, along with all other citizens of the United States, should be afforded the same opportunity to achieve their full potential, in accord with their individual abilities, in an atmosphere of equality and freedom.

ACKNOWLEDGEMENT

The Voice of the Retarded expresses its sincere appreciation to the distinguished members of the Committee on Finance of the United States Senate for the opportunity to express its views on this very important subject.

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NOTES AND BIBLIOGRAPHY

TESTIMONY OF SEPTEMBER 19, 1986

(1) "National Action to Combat Mental Retardation", Supt. of Documents, U.S. Government Printing Office, Washington D.C. October, 1962, p. 74.

(2) Federal Register, Vol. 51, No. 42, Tuesday, March 4, 1986. "Medicaid Program, Standards for ICR/MR Facilities".

(3) Smith, Mary F., "Residential and Community Services for Persons With Mental Retardation and Related Disabilities", Congressional Research Service, The Library of Congress, Wash. D.C., October 18, 1985, pp. 5-6.

(4) Braddock, David, Ph.D. "Challenges in Financing Community Integration in Wisconsin and the United States", Univ. of Illnois at Chicago, June 20, 1986, p. 27.

(5) Senate Bill 873, 99th Congress, 1st. Session, April 3, 1985

(6) Smith, ibid. p. 39.

(7) Smith, ibid. p. 4.

(8) Smith, ibid. p. 39.

(9) Senate Bill 1277, 99th Congress, 1st. Session, June 11,1985.

(10) Senate Bill 1948, 99th Congress, 1st. Session, December, 1985

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